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# Artificial Nutrition and Hydration for Persons in a State with Disorders of Consciousness

- an Updated Study in Theological Ethics Applied to Three Moral Cases.

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## **Abstract**

The Catholic Church has, over the past decade, given clear signals in the official teaching that one should not withdraw the artificial supply of nutrition and hydration from a person in a permanent vegetative state because this is not a medical treatment, but a basic human right. This master thesis considers not only the historical development, but above all the past decade's research, to investigate the advantages that the artificial supply of nutrition and hydration provide, in proportion to the burden placed on the unconscious patients. The thesis reflects on how strictly the Catholic Church's teaching should be interpreted, in light of the moral theological tradition, and the insights of the new findings. Deeper insights into different degrees of consciousness judged to be relevant to the ethical evaluation of three moral cases are of special interest.

## 1. Introduction

Let us imagine that your old good friend or relative is in a bed at the hospital and seems barely if at all able to communicate with the outside world. It turns out after a while that you are this person's closest relative. There is no one left alive who is closer kin to this person than you. The hospital asks you now how you wish to proceed. Would you like the treatment to continue? Would you like to prolong the life-saving assistance such as food or drink? Would you consider caring for this person alone or who else would provide care for him or her? Would you like to let this person die as painlessly as possible? Would you even consider helping this patient to die as smoothly and quickly as possible to relieve him or her of any painful experiences? What ought you be doing?

People are concerned about how dying patients are cared for, especially since the 1970s when euthanasia and physician-assisted suicide began gaining wider support. Some people are frightened to be either the executioner or executed if nutrition and hydration are removed during their illness or that of their dear ones. There has been an intense debate within the Catholic moral theology whether it seems morally right or not to continue the artificial nutrition and hydration (ANH) in cases where the patient has a serious brain injury and disorders of consciousness (DOC) that includes both patients in a vegetative state (VS) and those in a minimally conscious state (MCS).

This is an intricate question needing careful reflection. This thesis aims to give some ethical advice and guidance built on current research on the issue along with the traditional teachings of the Church.

### 1.1 Aim

The purpose with this master's thesis is to investigate whether contemporary research provides clearer ethical guidelines for when to provide artificial nutrition and hydration (ANH) to people in a state with disorders of consciousness.

## 1.2 Outline

After the introduction stated both the purpose and focus of the thesis, in chapter two the thesis presents the philosophical-ethical contradiction between wanting to preserve human life at any cost and the individual's autonomy over his or her life. The thesis will adopt an intermediate position in accordance with Catholic tradition and develop what this means.

Chapter three contains a presentation of three moral cases, which are related to the ethical problem of the thesis. One could say that the thesis focuses on the second of the three moral cases. The two other moral cases give to some extent the limits of the second case. Everything that is written could be read with this prism: what does it say about the second case.

In chapter four the chronological history of ethical attitudes will be delineated regarding eating and drinking at the end of life, mainly in the Catholic Church's sphere of thought. In chapter five an overview of the scientific question is presented. It serves also as an introduction for those who have not reflected on this specific ethical problem before.

Chapter six explains what a proportionate approach means and how it will be used on the master thesis' problem.

Chapter seven describes illusory similarities and real differences between the master thesis' issue and the question of whether euthanasia is beneficial or not. Chapter eight takes up the important question of who should decide, when someone becomes unconscious, whether to forego to give or withdraw the artificial supply of nourishment and drink given to the unconscious person. Chapter nine illuminates when it is futile to make use of artificial nutrients and drinks and ask if there is any distinction between foregoing or withdrawing artificial nutrition and hydration from an unconscious patient. Chapter ten summarizes the most important elements in discerning the thesis' ethical action.

In chapter eleven an ethical analysis is done of the three moral cases presented in chapter three. Then follows a closing summary and suggestions for further investigations in chapter twelve and finally a bibliography.



### 1.3 Literature review and material for research

The development and the main contributors concerning both the ethical question of artificial nutrition and hydration for patients and the more recent question of the vegetative state in medical literature will figure, be mentioned, or cited in the historical review of this thesis. Scientific articles in medicine and in philosophical or theological ethics have been used in this research project. The contribution of these authors is mainly to update the ethical reflection on the issue that is studied with the information provided by the latest and most interesting discoveries publicly referenced by scholars in peer-reviewed medical journals. Three of them have key importance to this thesis:

- *Quality of Life and Assisted Nutrition*, an article in philosophical ethics written in 2008 by Alfonso Gómez-Lobo, a thorough investigation in the collection *Artificial Nutrition and Hydration: The New Catholic Debate* edited by Christopher Tollefsen.
- *Catholic Teaching On Prolonging Life: Setting the Record Straight* written in 2001 by Michael Panicola, a good and inspiring example of how this type of research can be done.
- *Coma and consciousness: Paradigms (re)framed by neuroimaging* written in 2012 by Steven Laureys and Nicholas D. Schiff, offers contents and insights that had a decisive breakthrough on the orientation of this thesis when it came to determine how one ought to make a moral discernment of the question.

The inspiring writings of Lisa Cahill whose sharp discerning of different ethical questions from a scientific point of view is an eminent model for every writer wrestling with bioethical decisions.

Handbooks in fundamental theological ethics, especially *Reason informed by Faith* written in 1989 by Richard M. Gula have helped to undergird the ethical point of view of this thesis. Some church documents relevant to the topic are necessary, especially *Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration* written in 2007 by the Sacred Congregation for the Doctrine of the Faith.

## 1.4 Potential problems

In theological ethics it might be difficult finding a consistent ethical approach to problems involving firmly stated declarations from church authorities, and thus determining how faith harmonizes with reason and neurological science.

In the field of bioethics it is very difficult to find clear boundaries between what is permissible and impermissible, moral and immoral, proper and improper. That is one reason why the theological ethics are best exemplified with concrete cases where the facts are given to the greatest possible degree.

There is a challenge to embrace the ecumenical aspects of the problem: this thesis is written within the Catholic tradition and uses the language and methods common within that tradition. This will enable a discussion of particular aspects with precision and theological depth. A more ecumenical discussion is indeed desirable; however, it would require clarifications and a length that this study does not permit. Ethics never embrace only Catholics, and the dialogue must be between all people willing to participate and advance human progress. However, perceived boundaries do not go between the different confessions, but within them and discrepancies in views have more to do with contrasting philosophical conceptions. In the Pew Center's report *Religious Groups' Views on End-of-Life Issues* (Cooperman, Masci & O'Connell, 2013), an ecumenical and inter-religious investigation shows that there are no major differences between the traditions and there are sometimes discussions continuing within these traditions. All state that they are protecting life against euthanasia and assisted suicide; however, they do not believe in prolonging life if it gets too burdensome or disproportionate to do so. The Unitarian Universalist Association of Congregations passed a resolution in 1988 advocating *the right to self-determination in dying*, and therefore allowing everyone's conscience decide whether to make use of euthanasia or assisted suicide. Albeit this is an American survey, it reflects a world-wide state of minds and facts.

Most sources used to establish the moral cases are taken from newspapers or the internet, and not from scientific articles. This may be a disadvantage for the accuracy of moral cases, that is, on their correspondence to what has really happened. However, this does not influence on the integrity of the moral cases, which are constructed according to

what's judged as the most plausible chain of events, comparing different sources and establishing cases that were as coherent as possible. In the case of Mr Vincent Lambert, the choice has been made not to consider the allegations of a doctor, accused by the parents of maltreatment, that the motive inspiring the defense of ongoing treatment to their son would be the once missed opportunity to protect their young child from a sexual abuse from a traditionalistic priest and that they now wanted to amend. It was judged a doubtful rumour. Only the parents' traditional faith was retained as relevant for the case.

### 1.5 Expected outcome

The expectation is to show that an ethical method of proportionate reasoning would put the recent statements by the Sacred Congregation for the Doctrine of the Faith in perspective and that the apparent negative attitude to any removal of artificial nutrition and hydration would be mitigated.

## 2. Why? A Background: A context of a cultural conflict

There is a cultural battle going on regarding the question how to define human nature between claims of vitalism, the belief that human life is an absolute good to preserve at all cost, and claims of subjectivism, the belief that one's primary responsibility is to oneself and one's particular values, often expressed through a bioethical autonomy emphasis in the tradition of pessimistic utilitarianism.

The ethical landscape will in this chapter be clarified and the ethical horizon delineated for this thesis' moral issue. The Catholic tradition will in an Aristotelian way, be outlined like an elevated virtue in the middle of two vices, where one of them, deontological vitalism puts too much emphasis on biological life, and where the second, teleological pessimistic utilitarianism, does not protect biological life enough. Creation is a gift; however, that does not rule out a mature responsibility to care for this gift.

### 2.1 Deontological Vitalism

Vitalism, in a broader historical perspective, claimed that there is a principle of life. This principle is responsible for the growth, reproduction, evolution, and other functions of life. These functions could therefore be reproduced artificially. This principle of life states that nature cannot be entirely explained in physical or chemical terms. Two proponents of vitalism were the French philosopher Henri Bergson (1859-1941) and the German biologist Hans Driesch (1867-1941). A person's moral experience is living, according to Bergson. The moral emotion is based on the principle of life that gives a person's orientation, his *élan vital*. The emotion is not only psychological, but surpasses the individual human limitation and gives also a metaphysical foundation to morality. Bergson searched in emotion for the fundamental principle of morality. Emotion gives us a reason to explain why the moral person is an individual, why morality is an unsurpassed good, and why it mainly consists of a love for humanity. The aesthetic creation has its origin in emotion (Worms in Canto-Sperber, 2004a, 175).

Contemporary vitalism, more specifically, is related to medical health issues and has little in common with this earlier philosophical form of vitalism. Today, proponents of vitalism insist on the fact that everything must be done to preserve the biological life on

earth. Vitalism holds that human life is an absolute good that takes precedence over other goods and should be preserved at all costs. It is associated with a concept of well-being consisting of a set of objective goods: enjoyment, personal relations, life, understanding, accomplishment, and human dignity (Kelly, Magill & Have, 2013, 127-128).

This principle supersedes every wish of the patient, every consideration of cost and effectiveness by the society or burden to the proxies of the patient. Therefore, it might justly be considered a deontological belief, like a law that ought not to be overridden at any time. Who would contest that death is a source of anger and rebellion? Some vitalists conclude that death should be rejected by the law as far as possible.

The contemporary form of vitalism is sometimes found among relatives of patients who want the physician to continue therapy after it has ceased to be effective and has negative effects on the dying patient. They insist that life must be preserved, conserved and if possible, prolonged. The sections about euthanasia and autonomy will make it clear, however, that there are also persons arguing for a right to die.

## 2.2 Teleological Pessimistic Utilitarianism

Utilitarianism teaches that an action can be judged morally good or bad only because of its good or bad consequences, where the ends of an action are very important, and this is why utilitarianism often is labeled teleological, promoting the happiness of individuals. The pessimistic utilitarianism is the moral theory that qualifies a human action as good to the extent it minimizes pain, suffering and unhappiness, instead of (also) looking for the action that is maximizing happiness. Pain and suffering are often considered easier entities to deal with and to remedy. Pain is then more real than an illusive condition of happiness and alleviating pain is seen as a condition and first step towards happiness (Aveek, 2011). The pessimistic utilitarianism values life for its social usefulness and prefers ending life when it becomes frustrating, useless or burdensome (CHA, 1993, 48). It is about the freedom to act according to one's own desires, preferences, and choices. When a person's likeness to the image of God diminishes, for example, through a debilitating disease, life loses its inherent value and can be ended by personal choice (Coleman, 2014, 33). It is often combined with considering well-being consisting in

mental states: happiness, pleasure, and life-satisfaction, or a conception of happiness consisting in the satisfaction of one's desires or preferences. A utilitarian autonomy argument often stresses some qualities of life like the ability to be free and to communicate, think and reason over the inherent dignity of the human being and person (Laing, 2008, 77). Pessimistic utilitarianism is thus connected with the ethos of individualism, asserting that independence bestows humanity its dignity. The subjectivism of utilitarian pessimism equals thanatism, the will to cause death when deemed convenient. One may think this position an antipode to vitalism (Gomez-Lobo, 2008, 105-106, 109). However, autonomy claims are inscribed in a prior setting of dependence. Illness can feature the ontological dependence of human beings. They are dependent before they can become autonomous. Domination and independence make the person. With neither power nor independence the worth of the human life is questioned, or even denied by these pessimistic utilitarians. It would be a virtually sub-human quality of life, a perspective feared by many persons advocating the ontological dignity of the human person whoever and in whatever living condition that human being may be.

A problem with the pessimistic utilitarianism is that it strives for the absence of suffering, regardless of whether the suffering ameliorates the overall dimension of personal health or the human character generally. Another difficulty with the pessimistic utilitarianism is that one really cannot judge an action other than by its consequences, and how does one know the consequences of a person's death or future life, before the death has occurred or the life has been lived? The basic objection to utilitarianism as a moral philosophy consists in the doubt of how it treats the human person. The moral agent is regarded as a support for the utility, which means that relations between people are not generally regarded at all. Utilitarianism confuses impartiality with impersonality. Utilitarianism ignores human rights by ignoring a person's distinct and unique character and ignores human integrity with one's plans, deliberations and engagement in pursuit of public good. However, a person cannot be reduced to the most intensely sensed human preferences (Canto-Sperber, 2004b, p. 2001-2002). In the western-world health care, utilitarianism is the dominant underlying ideology, where those who are the responsible caregivers search the greatest good for a greater number of patients and measure the

efficiency of the care given by the results, although there are many other influences too; e.g., from the deontological axioms invoked or from Catholic institutions who are trying to live by the tradition of the Church. This being said, there are also, as will be highlighted in this thesis, many doctors that strive to use new technological and medical achievements as much as possible, and not always to the benefit of an improved general health condition of the patients.

### 2.3 The Catholic moral tradition

The Catholic tradition avoids these two extremes and finds the golden mean between and above them. It is in relation to both the man's personal salvation and to life of happiness with the eternal God in heaven. Life is in the Catholic tradition a gift of God. The obligation to conserve life is balanced by other obligations and by the love of God (Wildes, 1996, 502). The Catholic tradition emphasizes the fundamental or intrinsic dignity of every human person while considering well-being like a human flourishing or like certain life values. The fact that a human being exists means that the human being has a dignity. This dignity does not depend on man's abilities, or the freedom and opportunity to practice these skills. "A flourishing human being is one who possesses, develops, and enjoys the exercise of cognitive, affective, sensory, and social powers, no less than physical powers" (Hausman, 2015).

This Catholic tradition shares with the utilitarian tradition the importance of a goal in life. The goal is however often perceived in a different way and safeguarded by the intrinsic value of the human person. Human flourishing is the fulfilling of the person, maximizing human freedom and creativity; and the human person is somebody who can list preferred needs, corresponding to this person's well-being and flourishing. This fact provides an objective norm, which rescues Catholic personalism from totally being subdued by subjectivism, and instead allows diverse paths to the same goal or purpose, depending on circumstances. The Catholic tradition of ethics may be founded in the real goods and needs of actual human persons; these can be verified scientifically and experientially, and they can change from one historical or cultural context to another and depend on communications and the virtue of living together in the society (Bouchard,

2007, 21-22). Promoting life is enough to justify choices, actions and norms. However, the good of life is a limited good because it is the ground for striving after the higher, more important spiritual goods of life that is the love of God and the love of neighbor (Panicola, 2001b, 29).

The Catholic tradition defends, along with the vitalist tradition, an utmost respect for life. The person maintains the good of life as long as the patient lives. This good is not altered. For a believing person, however, life is only changed and not ended by death. To die would be to enter a transformed life. However, to assert that life is an inalterably good thing is not equal to saying that biological life is an absolute good that has to be preserved at every cost and over other good or good forms of life. It is rational to pursue, protect and contribute to human life; however, it is also rational under some circumstances to let the biological life change and to prefer other aspects of the person's life, like the person's spiritual, intellectual and free life with the condition that one does never intentionally weaken or destroy a biological life (Gomez-Lobo, 2008, 105). The Catholic moral tradition avoids medical vitalism, since this approach emphasizes technological means over the moral and spiritual goals of facing death in an authentic and reflected way. Human life is limited and imperfect, sometimes even through a person's fault; death has a part in this lack of perfection and is a normal human event in a life that includes spiritual life that will transform a person's entire existence (Coleman, 2014, 37). The overall general purpose of life is indeed living and furthermore living in a charitable friendship with God (ST IIa IIae q. 23 a. 1).

The original hospice philosophy was indeed intertwined with this Catholic tradition when it underscored connectedness, community, inclusion, and belonging as important values for the patient, and the need of a holistic view. The common expression of *total pain* in this hospice philosophy includes physical, emotional, social, and spiritual elements (Have & Jos, 2014, 132-133). Some patients are more in need of compassion, comfort and company than treatment and diagnostic procedures (Shannon & Ward, 1988, 632). According to the Catholic tradition patient autonomy includes a right to refuse treatment and to choose from among medically justifiable options; it is not a right to demand treatment (Drane and Coulehan, 1993, 29).



### 2.3.1 The human person

The Catholic tradition shares with the deontological tradition a willingness to protect the human life from haphazard decisions with a deadly outcome. Therefore, it might be relevant to underline the intrinsic value of the human person within the Catholic tradition: The human person understood as the image of God carries within itself a driving force for the human-divine relationship with its self-understanding, limits, freedoms, and love. The death of human persons would be a loss to the individuals and to the community. Continued care promotes the participation in the patient's life, communion, and solidarity. Persons do not have the moral obligation to help everybody; however, when the responsibility to take care of a human being is not impossible, ineffective, excessively burdensome to anyone in relation to the patient, then it is one's duty to do so. To intentionally neglect to take care of a person in need; for example, not feeding this person, would be killing the person. However, is to continue the biological life of some persons, receiving unconsciously the love and grace of God, whose loving gaze continues to fall upon them a sufficient reason and are the considerations from people visiting the living body really sufficient reasons to advocate that the human existence ought to continue and hopefully flourish? The question is whether this can be done only in this earthly existence of life or in another form of life too.

If someone lacks the ability to strive for human acts, then this person can no longer strive for the purpose of human life. The ability to perform a human act is the capacity now, or in the future, to perform acts of cognitive-affective function. If it is morally certain that persons cannot and will not perform acts of this nature now or in the future, then the moral imperative to prolong their lives no longer is present... Moreover, health care seeks to help people strive for the purpose of life, not merely to function at the biological level... Finally, this opinion [that the purpose of human life is friendship with God; i.e. charity, and not the biological life in itself without the possibility to perform human acts striving for achieving this purpose and fulfill one's part in the reciprocal relationship of friendship, is a positive reason for withholding

assent from the allocution] is based upon the firm conviction that human life is not an absolute good and that there is life after death, when as the Liturgy of the Mass for the Dead explains: "Life is changed, not ended" (O'Rourke, 2008a, 174-175).

### 2.3.2 The sanctity of life

The sanctity of life is an expression of the Catholic tradition. This principle states that each person is of an inestimable value and has a dignity from the fact that the human person is an image of God, free in Jesus Christ to participate in the divine life offered by his redemption and called to a trinitarian communion of life. The value of life is sacred and inestimable. Preservation of human life ought thus to be an important goal, especially to all medical professionals. However, human life is not an absolute good for a Christian. The witness of the martyrs shows that fidelity to Christ is more important in order to respect the sanctity both of the human life and the sanctity of God.

### 2.3.3 The basic good of life

Some authors within the Catholic tradition let the patient's inherent dignity prevail over other considerations (John Paul II in his speech from March 2004, according to Doerflinger, 2004, 2-4 in Cahill, 2006, 125), or claim that there are no higher spiritual goods. Cataldo maintains that the duty to preserve life has always been regarded independent of the presence of personal and spiritual capacities. (Cataldo, 2004, 536 in Cahill, 2006, 126), or at least no hierarchy of spiritual goods (Latkovic, 2005, 512 in Cahill, 2004, 126), advancing that human life is an untouchable basic good (Finnis and Grisez according to Cahill, 2006, 126).

Other authors claim that while physical life is a real and true good, and not only since it is instrumental to higher purposes, it is also a limited good. Meulenbergs and Schotsmans recognize that "patients might continue to pursue material, moral and spiritual values in some fashion that transcends physical life" (2005, 135 in Cahill, 2006, 126). Biggar distinguishes merely biological from biographical life (2004, 56 in Cahill, 2006, 126).

Biological human life is not the ultimate value according to the Catholic ethical tradition. God, values and virtues, an individual's personhood and history, a person's grace-filled realization of his or her life and its fulfillment of joy, charity and peace transcend the biological life. To make biological life the ultimate value is to forget the real priorities of a human being, making an idol of what is not communion with God. A basic good exists only in relation to other basic goods, and sometimes one has to discern a choice which basic good to favor presently, or how to best prolong and promote life.

#### 2.3.4 The qualities of life

Whether the Catholic tradition is compatible with considerations about the qualities of life has been a much discussed subject in the academic ethical literature. The expression quality of life connotes a variety of senses. It implies that there are different qualities of life, which can be ranged on a scale and evaluated. In Ancient philosophy, the quest for a good (quality of) life was considerable and a cornerstone in the ethics of the Greek civilization.

Quality of life can mean either the relationship between humans and God and in this more metaphysical sense, everyone has the same quality of life, since everyone is equally loved by God and finds their dignity in this love, or it means the quality of human functions, and these qualities depend on which measures for human life that one considers, upon the dispositions of the subject judging these functions and the criteria set up for measuring these human functions. Quality of life can also mean how one's life is felt and experienced, thus relying on the discernment of the patient (Ashley, 2006, 189).

Within the second and maybe also the third sense of quality of life just mentioned; happiness, human flourishing, and enjoying life are three qualities of life highly appreciated and remains such by most people. Mental disabilities, physical handicaps, or social misery would be impediments to this good life and would be ranked as equal to a poorer quality of life. The dilemma with this type of quality of life definition is that it is quite impossible to be united around an equal evaluation between different qualities. It is the same difficulty that an ethic of virtue also encounters. Which qualities of life or which virtues are one going to choose to be a good person? The qualities of life selected will vary

between cultures, classes, traditions, and genders. Some will magnify some qualities that will be despised by others (Gomez-Lobo, 2008, 103).

To have a better or worse quality of life is not equal to have a better or worse condition of health. A patient's condition of health appertains to the medical professions to establish, in searching for the best way to ameliorate or maintain the health of the patient. This state of health is something more narrow than the qualities of life a person enjoys, and medical professionals alone cannot judge these qualities of life. Patients in Post Coma Unresponsiveness (PCU) have few physical qualities of life and their state of health is very poor, though it might be stable. Not being able to enjoy pleasures does not justify being put aside or not valued as a person, since the patient still has many inherent qualities of life, like those of being, having relationships, friendships, having a history that partly is common with others and having an identity of one's own (Gomez-Lobo, 2008, 103-104). Therefore, it is better to avoid the perilous utilitarian views on the notion quality-of-life.

Quality-of-life considerations, evaluative and normative assessments do not seem to be able to include something concerning the relation between the patient's general condition and one's ability to pursue material, moral, and spiritual values which transcend physical life but do not accord that life its very meaning and distinction. It is not a sufficient reason that a person has a poor quality of life to forego or withhold a treatment. The causes reducing life's quality must be direct consequences of an irreversible physical condition to make a choice of interrupting someone's treatment and let this person die (Cahill, 1987, 114, 121).

The ethical landscape, which has been delineated so far has in common that almost all involved are committed to the life of the suffering person to be as good as possible considering the economic possibilities. This thesis will make use of the Catholic ethical framework of tradition to illuminate the issue we are studying. Let us then examine more closely three concrete moral cases for which circumstances and conditions can be better clarified which is a necessary prerequisite to provide some good ethical advice.

### 3. Whom it is about: Three Moral Cases concerning ANH

#### 3.1 Aruna Shanbaug

Ms. Aruna Shanbaug (1948-2015) was an Indian nurse at the hospital in Mumbai engaged to a medical doctor. A ward attendant attacked Ms. Shanbaug on November 27, 1973, while she was working at night in the hospital ("Aruna Shanbaug: Brain-damaged", 2015 & Pärsson, 2015). Ms. Shanbaug was raped and strangled while she was changing her clothes in the hospital basement and, because of a severe brain injury, was left blind and paralyzed. The contract staff member who was employed as a sweeper, strangled her using a dog chain. The perpetrator stated, after Ms. Shanbaug died, that the attack was caused by anger. They had personal relationship problems, including disagreements on employment conditions: It was claimed that Ms. Shanbaug had been rude to the cleaner by forcing him to feed the dogs, despite his dog phobia, and by refusing him vacation time to visit a sick elderly relative. He claimed that this was the cause of his outbursts of anger and rash behavior. The perpetrator has denied and continues to deny the accusation of raping her (Chatterjee, 2015). Ms. Shanbaug choked resulting in deprived oxygen supply to the brain. She also suffered a brain stem contusion injury, a cervical cord injury and cortical blindness (Kurup, 2006).

The following morning she was discovered by one of the cleaning staff with blood all over and around her. The police first labeled the incident as theft and attempted murder. The doctors hid the fact that an anal rape had occurred, presumably to prevent Ms. Shanbaug from social deprecation and to prevent adverse effects on her impending wedding. After the attack, the nurses in Mumbai went on strike demanding better working conditions.

Ms. Shanbaug spent 42 years in a vegetative state after the attack. She was nourished artificially through nasogastric intubation twice a day. The municipality tried to remove her from the hospital, but the nurses protested and Ms. Shanbaug remained in hospital care. She accepted food and responded with facial movements, according to a hospital spokesperson. Certain nurses said that she screamed in fear when someone approached her. Her condition deteriorated over the years. Probably, this had other causes beyond the fact that she was aging.

After a few years, neither her relatives, nor her future husband maintained any contact with Aruna, and some considered Ms. Shanbaug like a virtually dead person.

In 2011 the Supreme Court of India rejected the plea for euthanasia filed by a journalist friend, Ms. Pinki Virani. The nurses celebrated this verdict by distributing sweets and chanting slogans. They hugged and congratulated each other ("India court", 2011). However, the Supreme Court thereafter allowed passive euthanasia in India. It is an archaic, rather unfortunate use of the term euthanasia for allowing someone to die in a justified way. Today someone practicing euthanasia would normally have both the intent and the purpose to willingly abridge another person's life. When the Supreme Court of India allows passive euthanasia, there is no such intent or purpose. It was permitted to withdraw nutrition and hydration from terminally ill patients who were enabled to live longer in a vegetative state or in another analogous condition by the artificial nutrition and hydration (Magnier, 2011).

Ms. Shanbaug died after six days of pneumonia on May 18, 2015 (Anonymous, 2015a & Pärsson, 2015). She was moved to the medical intensive care unit of the hospital and put on a ventilator. It is unclear whether the nutrition and hydration were removed, since no written source about this has been found. However, there are images from a video indicating that they were not removed ("Aruna Shanbaug, in", 2015). The question is whether it was a morally sound decision to keep her in a vegetative state for such a long time with artificial nutrition and hydration, or would it have been morally sound to stop it earlier.

### 3.2 Vincent Lambert

In 2008 Vincent Lambert suffered a traffic accident that left him in coma, which in a few weeks time evolved to a minimally conscious state (MCS +).

In 2011, medical experts at the Science Group of Liège discovered that Mr. Lambert could feel pain and other sensory stimuli; they also found that Mr. Lambert could voluntarily control his respiration. In Reims doctors were unable to establish any communication because the answers Mr. Lambert gave were too diverse to be understandable. Mr. Lambert was not on any life-support, however, since he had difficulty swallowing correctly, the medical staff gave him artificial nutrition and hydration.

In 2012, health care workers observed behavioral manifestations, which they conjectured could be interpreted as an opposition to grooming. This amounted, in their view, to be a rejection of life. Following these findings, and based on the analysis he made of the absence of a favorable neurological evolution of the patient, the doctor in charge of Mr. Lambert chose to implement the collegiate procedure, a French term for when the court sits as a bench comprising a president and two other judges, to limit or stop the treatment and the artificial maintenance of life (CSP, 2010).

On April 10, 2013, the doctors responsible for Mr. Lambert decided to interrupt the artificial supply of nourishment and drink. It was done with his wife's consent, but without approval from the other family members. Their rationale was the unreasonable obstinacy (or futility, see section 9.1) of the treatment given to Vincent Lambert. Because the physicians did not consult the rest of the family, the doctor's decision at the University Hospital of Reims was overridden by the Administrative Court in Chalons-en-Champagne. The artificial nutrition and hydration began to be administered again seventeen days after it has been withheld.

In September 2013 the physicians initiated a new procedure for the end of life regarding Vincent Lambert, and then informed the whole family. The doctors again concluded that they should discontinue artificial nutrition and hydration. Two factions of the family started a battle concerning whether this is morally good or morally bad. On one side were Mr. Lambert's wife, the doctors responsible for Mr. Lambert's treatment and six of his siblings. On the opposing side were Mr. Lambert's very Catholic parents and two

siblings. A new procedure was started to withhold the artificial nutrition and hydration, with the whole family being aware of the facts this time; however, the Administrative Court cancelled the decision again. The court stated that the treatment was neither futile nor disproportionate and the function of the treatment was not only that of maintaining life. The opinion of the court was that it was wrong for the doctor in charge to assume that Mr. Lambert would like to end the treatment.

There is currently a dispute whether Vincent Lambert is still in a minimally conscious state or in a vegetative state. Most physicians claim he has degraded into a vegetative state. However, there are those who say that first these boundaries are ambiguous, and second that a little degradation thus cannot be so certain; there is no evidence of such a certainty (Madouas, 2015). On May 26, 2014 the medical experts drew the conclusion that Mr. Lambert was in a vegetative state, with problems of swallowing and a greatly reduced motor function in all four limbs. There were some problems that prevented the brain stem from functioning normally, but the patient could maintain the respiratory function. Since 2011, the situation has changed so that there are no longer any fluctuations in consciousness. The experiments with therapy to activate the state of consciousness further have failed. It seems as if the state of consciousness has deteriorated. Given the brain atrophy and damage which have been found and given the lapse of the five and a half years since the accident occurred, the doctors discerned that the damage is probably irreversible. Vincent Lambert responds to care and to certain stimuli, but the behavior indicates that it is probably not a question of conscious response, nor signs of an experienced suffering. It appears that there is no conscious manifestation or intention to either extend or terminate life-sustaining treatment.

The Council of State approved the measures of the hospital and overruled the decision of the Administrative Court. The Council found that Mr. Lambert was in a vegetative state, and it considered artificial nutrition and hydration a treatment that could be removed when it constitutes an unreasonable obstinacy (CÉJA, 2014 and Béguin & Clavreul, 2014). The part of the family opposed to discontinuing artificial nutrition and hydration challenged the imprecision of the term unreasonable obstinacy and regarded artificial nutrition and hydration as a care. They denied the vegetative state of Mr.



Lambert. However, there was no proof that Mr. Lambert was in a minimally conscious state, according to the Council of State. It was furthermore ambiguous to the family whether it is a morally good thing to withdraw nutrition and hydration from someone who otherwise is not imminently dying and to let somebody die from starvation and dehydration.

On June 5, 2015, the European Court of Human Rights ruled that the doctors' decision was consistent with the second article of the European Convention on Human Rights concerning the right to life (twelve votes against five with another judgment).

On July 15, 2015, the University Hospital of Reims started a new attempt to withdraw the artificial nutrition and hydration. The parents sued the hospital for refusing access to their son and for attempting murder. The bishops of the region of Rhône-Alpes were for keeping Mr. Lambert alive. The bishop of Reims, however, had confidence in the doctors' judgement (Chaland & Lamoureux, 2015).

On July 23, 2015, the University Hospital of Reims decided not to make a new attempt to withhold nutrition and hydration, because there were not the prerequisites of peace and security necessary to conduct such a procedure. The doctor responsible for Mr. Lambert demanded someone legally responsible to protect the patient's rights and the necessary security precautions to protect Mr. Lambert from being taken away.

On October 9, 2015 the Administrative Justice rejected the appeal to the court made by the nephew of Vincent Lambert requesting the cessation of the treatment, considering that only his family doctor had the authority to make this type of decision ("Vincent Lambert", 2015).

On March 10, 2016 the guardianship judge (le juge à tutelles) decided to let Mr. Lambert's wife, Rachel Lambert become Mr Lambert's legal representative, together with the department of Marne's regional union of families' associations, Udaf (l'Union départementale des associations familiales) as the sub-representative. It was the hospital in Reims who requested a general protection for Mr Lambert and that a referent would be appointed, which could represent Mr Lambert legally. His wife, Mrs Lambert was always considered to have had Mr Lambert's best interests at heart. The representative was appointed for ten years, since science cannot currently assume that Mr Lambert's

deteriorating health will change for the better within this time period. This was received with relief by Mr. Lambert's wife and nephew. The parents' lawyer announced that this decision was a disappointment and went against the hope that an independent third party would be appointed a legal representative. The verdict will be appealed by the parents' lawyer and new proceedings for mismanagement, illegal procedure, and attempted murder will now start. The fact that Mrs Lambert is appointed Mr Lambert's legal representative does not mean that Mr. Lambert not will receive ANH any longer. The guardianship judge did not decide instead of the judge on where Mr. Lambert ought to be cared for and did not decide which medical care the terminally ill patient ought to receive.

### 3.3 Terry Wallis

Terry Wallis is a man living in the Ozark Mountains of Arkansas who had a major car accident some weeks after he had become a father in July of 1984. He was then 20 years old. Mr. Wallis' truck smashed into a railing fence near a dry riverbed in Stone County, Arkansas where the truck later was found upside down. Mr. Wallis fell 25 feet and was found unresponsive and immobilized but still breathing. Mr. Wallis went into a coma that lasted for a couple of weeks. After the coma Mr. Wallis went into a vegetative state with the sleep-wake cycles and some reflex movements but with no awareness of what was happening around him and no sense of pain, insofar as the doctors could tell. He then progressed within a year, to a minimally conscious state, in which he exhibited some tiny voluntary movements, like smiling; reacting when something was shown or said, albeit not necessarily in an expected way; and following objects with his eyes. He also exhibited a perception of pain. Sometimes Mr. Wallis was conscious, while other times he did not seem to be conscious. It was difficult to say whether he knew what was happening around him. Unlike locked-in state patients who are aware of what is happening around them although they cannot express themselves and communicate with their surroundings in a perceivable way, Mr. Wallis does not remember, now that he has woken up, what happened to him while he could not communicate with those around him. Mr. Wallis became more and more conscious, as more and more connections were reestablished between different parts of his brain. He woke up twenty years after the car accident and this indicates that it is possible to regenerate the small projections of nerve cells or axons and to recover normal brain metabolism after a traumatic cranial injury and a generalized and progressive brain atrophy. Mr. Wallis developed a higher interactivity between the different parts of his brain: the axons were regenerated. Medical doctor Steven Laureys, a

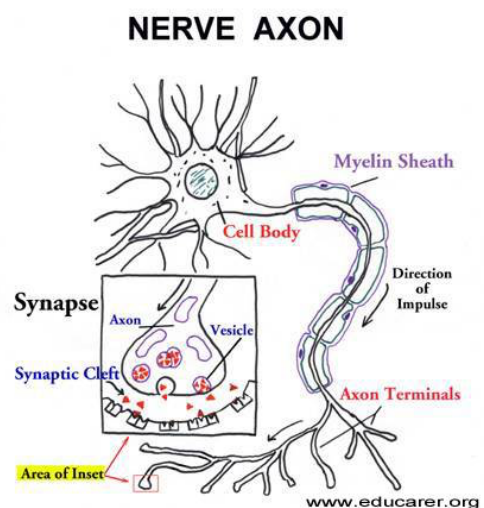


Image 1: A nerve cell  
Source: Porter, Phyllis:  
<http://www.educarer.com/brain.htm>  
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specialist in neurology and states of consciousness, thinks this has happened maybe ten times in the human history. This happens only in very rare instances, and ought not to evoke false hopes in many anxious relatives of minimally conscious state patients. Despite the odds, however, Mr. Wallis is today enjoying living ("Sorti de", 2006).

Mr. Wallis's frontal lobes were badly damaged in the accident. The frontal lobes process experience, and turn it into memory. The reason Terry thinks he can walk when he cannot is that the frontal lobes cannot process the information that his body is not walking any more. His understanding of himself and the world around him seldom gets updated and Mr. Wallis often needs to help understand his situation. One of their functions is the censorship of the primal instincts of a human being such as sexual urges and aggression: When his speech therapist asked him what she could do for him, he said: "Make love to me". Still, his memory continues to improve. Mr. Wallis is nevertheless grateful to be alive and to be able to communicate with his family and all those that he meets: He has been called a modern day Lazarus. The specialists are certain that an important factor in his recovery was the constant love and attention from his mother and family (Stephen, 2015).

## 4. Catholic moral history of allowing to die.

Moral theologians throughout church history have pondered over how to interpret the commandment not to kill; this history will be outlined in this chapter, from Antiquity to contemporary debate with a strong emphasis on the discussions and the discoveries from the 1950s and forward.

### 4.1 Ancient history

The Hippocratic Oath reflected former efforts to demarcate the objective of the medical profession as something good, to save lives. Ancient thinkers, Christian Fathers of the Church and theological scholars have meditated on why life is worth living (Aristotle, Aquinas), the dangers of fasting too much (Jerome), and the intentions of life (Abelard). They have contemplated upon a human person's holiness since the human person is God's image (1 Mos 3; Iraeneus) and whether this wonderful resemblance means that one in no way can restrict one's efforts to preserve another person's quality of life.

When the discipline of moral theology became distinguished from its roots in dogmatic theology in the beginning of the late fifteenth century, early modern moral theologians began to examine more systematically the question of how nutrient intake can be a mandatory way to exercise the love of and preservation of the life of oneself or one's neighbor. Catholic moral theologians have reflected on the circumstances, situations and conditions under which the obligation to preserve life is binding and about which interventions intended to prolong and to preserve life are obligatory (Shannon, 2008, 899).

Francisco de Vitoria (1486-1546), a Spanish Dominican theologian, considered the limitations of such an obligation from the perspective of its ethical foundations and different circumstances, such as morally impossible means, too difficult or dangerous means, too painful medical situations, too repugnant means according to the patient's reaction to the treatment, or too expensive means considering one's economic situation and according to the reasonable judgments of prudent and conscientious men (Wildes, 1996, 503-505). Vitoria made a very important distinction between morally binding and optional means. Health is an important concern of a human person, but it ought not to be the most important issue in life and a disproportionate important concern for any person

(Fleming, 2008, 99-107). If the sick person finds eating excessively burdensome, or if the quantity or the quality of food required to gain health exceeds the normal ways of eating, for the person in question, then taking food might be a disproportionate or morally optional means and not a morally binding obligation (cf. Paris, 2006, 118).

Domingo Bañez (1528-1604), a Spanish Dominican theologian, introduced the terms of ordinary and extraordinary means, a distinction that became well-anchored in the Catholic tradition, and its practical relevance is still important today. The Spanish Jesuit theologian John de Lugo (1583-1660) interpreted the distinction to be that one is only morally obliged to use ordinary means to preserve life and then only if there is some hope of benefit and some degree of duration. The means are ordinary in relation to one's condition and state in life or, according to saint Alphonsus de Liguori (1696-1787) to the subjective level of repugnance one experiences using one of these means (Panicola, 2001a, 16-17).

Leonardus Lessius (1554-1623), a Flemish Jesuit moral theologian, sought after the virtuous golden mean between an excessive care that does not help the person in need and a negligent *laissez-faire*. The discussion around artificial nutrition must not only consider the unequal access to food around the world to give the opportunity to everyone to overcome the miseries of obesity and hunger; it would also benefit from a perspective of resurrection of the bodies in the light of the ultimate end: to sustain the health by nutrition is neither an absolute obligation, nor the ultimate goal of a believing Christian (Fleming, 2008, 99, 114-115). Ordinary means generally offer some hope of benefit, worthwhile both in quality and duration. To qualify as ordinary means, they ought to be common and not difficult to achieve for a certain person in his or her specific condition or position, hence being both convenient and reasonable for that person.

#### 4.2 Before Pius XII

A more general use of artificial respiration led to patients with brain damage being able to survive their brain damage in the 1950s. Patients were defined being in coma or in a locked-in state and some patients were even able to reawaken from their coma, although remaining without signs of awareness or communication (Laureys & Schiff, 2012, 479). In the mid-twentieth century the American Jesuit theologian Gerald Kelly summarised the traditional distinction of ordinary and extraordinary means in this way:

By ordinary they mean such things as can be obtained and used without great difficulty. By extraordinary they mean everything which involves excessive difficulty by reason of physical pain, repugnance, expense, and so forth. In other words, an extraordinary means is one which prudent men would consider at least morally impossible with reference to the duty of preserving one's life (Kelly, 1950, 204).

The foregoing definitions do not avoid all difficulties. There is always difficulty in estimating such factors as "excessive," "reasonable hope," "proportionate benefit," and so forth. But this difficulty seems inherent in all attempts to make human estimates, and it is doubtful that we can ever attain to a formulation that will entirely remove this problem (Kelly, 1951, 550-551).

Kelly was of the opinion that human persons do not always have to use even ordinary means to prolong life, when there is no reasonable hope of benefit and it would seem useless. Usefulness is the criterion that should be used to differentiate ordinary from extraordinary means. ANH thus becomes an extraordinary means once there is little hope of benefits, due to a PVS patient's poor condition and prognosis. Once it is medically established that the unconscious state is likely to be irreversible, one has no obligation to continue the medical treatment. Pope Pius XII would sanction this view of thought.

#### 4.3 Pius XII

Pope Pius XII first established that there is a duty to take care of one's health with the purpose to conserve life in a severe illness. This duty of care extends to those who are in a close relationship to oneself: family and dear friends, and in a certain extent also to the members of the whole society, within the realm of social justice. He stated that this duty does not extend to all forms of care in a mandatory form:

Normally one is held to use only ordinary means [to prolong life] – according to the circumstances of persons, places, times, and culture – that is to say, means that do not involve any grave burdens for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more

important good too difficult. Life, health, all temporal activities, are in fact subordinated to spiritual ends. Moreover, it is not forbidden to do more than is strictly necessary to maintain life and health, provided that one does not miss to accomplish more serious duties (Pius XII, 1957 translation in May, 2008, 65).

One is not required to use more than ordinary means, which are proportionate to the benefits of the general health condition of the patients, and whether it is proportionate or not and thus can be qualified as ordinary. This depends on who one is, where one lives, in which cultural climate one is integrated and to which culture one appertains. The circumstances of an act play an important role depending on a person's place, time, culture etc., and not only on an intervention's scientific grounds, success, or availability. By the time of this allocution most people, especially in end of life situations, would have preferred to be treated only with ordinary means that are morally mandatory (Smith, 2008, 10). Nobody is bound to use extraordinary means, which are not proportionate to the benefits for the patient in relation to the burdens of the patient and the patient's surrounding proxies, and hence do not enable the person to strive for the spiritual purpose of life, to make judgements and free choices (May, 2008, 65). Another course of action, the pope writes, would be too burdensome for the ordinary man, and would impose too heavy burdens on men and women when it comes to the acquisition of the more important virtues and goals of heaven. The statement that temporal activities like life and health are subordinated to spiritual ends, without curtailing anyone's opportunity to do more than necessary, certainly implies a proportionate way of thinking: only if the conservation of physical life and the improvements of health are proportionate to the efforts invested in the cure and justifying sacrifices made by the patient and the proxies, then the cure is to be taken. What is important is whether a means is proportionate to the efforts employed in attaining the preservation of life.

#### 4.4 In the spirit of Vatican II

In 1972 Jenett and Plum defined the Persistent Vegetative State (PVS) with the intention of identifying patients with only residual autonomic nervous functioning



originating at a brain stem level like sleep-wake cycles, functioning respiration, digestion, and thermoregulation (Laureys and Schiff, 2012, 479; Jennet and Plum, 1972, 734).

The Congregation for the Doctrine of Faith (CDF) confirmed further that a proportionate reasoning is appropriate regarding the issue of whether the artificial nutrition and hydration ought to be given. In the Congregation for the doctrine of Faith's Declaration on Euthanasia from 1980, CDF finds that the terms ordinary and extraordinary might be less clear than the terms proportionate and disproportionate. The CDF considers medical means to be proportionate when "studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources" (CDF, 1980, § IV). It may seem that it would be rather simple then to establish which medical means are morally binding to use, coinciding with the means that are proportionate. However, it is fairly difficult to determine in concrete cases, especially VS cases, where patients cannot decide for themselves.

Food can, when administered and supervised by medical professionals and geared toward restoring a vital physiological function, be the equivalent of medical means and the question is whether ANH belongs to the proportionate means for VS patients? The responses to this question have been very diverse. The New Jersey Catholic Conference argued in 1989 that ANH is a basic means to human life, and always ought to be provided. Handling otherwise would be pushing patients to starvation, dehydration and death. The defenders of such basic rights want to put forward a framework protecting the value of the moral person, and hindering the society from a slippery slope that could be leading eventually to voluntary euthanasia (NJCC, 1989, 582-584 in Panicola, 2001a, 19-20). Texas Catholic Bishops with the Texas Conference of Catholic Health Facilities stated in 1990 that sometimes the medical condition of the patient is such that the burdens outweigh the benefits and thus diminishes or removes the obligation to use the medical means available. The consequences for the VS patients of this approach that for anyone not used to consider these question may sound as utilitarian while they are conformed to the statements above of the CDF. According to the authors of this text such decisions can be made only after a

serious contemplation of the best medical and personal information available, be specific to each case, and always include nursing care in order to maintain personal dignity and hygiene (TCB & TCCHF, 1990, 54 in Panicola, 2001a, 20). The National Conference of Catholic Bishops Committee for Pro-Life Activities stated in 1992 that one ought to have a presumption for medically ANH, and only withdraw it after careful examination, when there is no reasonable hope of sustaining life or when it involves disproportionate risks or burdens for those involved (NCCBCPLA, 1992, 710 in Panicola, 2001a, 20). This diversity of opinions on this subject of discussion has remained almost the same during the last twenty-five years.

Thus, there are two basic and disagreeing schools of thought, with a span of diversity of opinions each, have emerged within Catholicism: an absolute or strong presumption for ANH; and a presumption that the worth of ANH is seriously compromised if the quality of life of the whole VS patient is very poor (Cahill, 1991, 110).

The former school finds that ANH appertains to normal care, or basic nursing care, and points to the risk that making ANH optional for VS patients could create a threat to other patient groups also, like those persons who suffer from different disabilities. Either it is always mandatory, or there is an exception for when ANH is useless, that is, the patient is imminently dying or no longer able to assimilate ANH, or there is also an exception from the presumption, when it is not only useless, but also too burdensome in itself for the patient. Some of this school's adherents contend that "to cause death by removal of artificial nutrition is to directly intend death itself as one's goal, creating the moral equivalent of mercy killing" (Barry, 1989, 1-30 in Cahill, 1991, 113) or deliberate starvation.

The latter school does not group ANH among pro-life issues like euthanasia and abortion and finds that ANH is not morally required for PVS patients. Genuine concern for the welfare of the PVS patient, then, does not seem to be a duty, but rather an encumbrance to the continuance of life by ANH. This school concentrates their reflection around the intention to avoid artificially continuing a situation where the humanity of the person is heavily reduced. ANH is artificial and a depersonalized manner of feeding when integrated functioning has ceased. Can it then really be labeled basic nursing care or is this

rather a technological means? Normally, this later opinion does exclude euthanasia in whatever form it appears.

There is a third alternative; however, not very Catholic, though it is practiced in formerly majoritarian Catholic countries, like Belgium: that is the opinion that euthanasia is permitted and therefore the foregoing or withdrawal of ANH is only subject to personal preferences depending on professional judgements. Nowadays many are those who define euthanasia as "an act or an omission, which of itself or by intention, brings about death so that suffering may be eliminated" (Smith, 2008, 10). However, this is not according to the Catholic tradition and is not what either the former or the later school advocates.

Panicola finds that these differences apart, there can be a concordant consensus about the view that human life is a basic but limited good and that treatment must offer a hope of benefit, then this would imply for PVS patients, for whom according to Panicola, the ability to pursue spiritual goods of life has been totally eclipsed (2001, 21), one has no duty to protect or preserve their lives. They have reached a point beyond treatment including ANH and ought to receive only supporting nursing care and be allowed to die in peace. Some authors would question the statement that the ability to pursue spiritual goods has totally eclipsed. These authors fail to realize that one has to weigh goods to reach a holistic decision regarding the integral person of the patient, and that biological life is not all the life the human person is: there is also a loving life, an experienced life, and a shared, participated social life. Biological life is indeed a good, however, not an absolute good. Letting biological survival be the normative or ultimate value in decision-making is nearly making an idol of biological life, because physical life is then given an importance beyond its created status. Physical life is made an ultimate good rather than remaining a limited and dependent good (Shannon, 2008, 897). Such a view would have devastating consequences with excessive burdens in health care. The ultimate good in the Catholic view is to enter in communion with God through loving others like oneself, and the physiological, psychological, social, and spiritual goods are there to assure that this communion is realized, continues, and is accomplished. ANH sustains only biological life to PVS patients, and "does not restore these patients to a relative state of health" (Panicola, 2001a, 22). They will never experience life to the extent that they will be able to pursue

spiritual goods. May objects instead that many people, from seriously handicapped children to mentally impaired adults find themselves belonging to those who are unable to realize the spiritual goal of life. There are however those who would deny that these persons are unable to realize spiritual goals (May, 2005, 541-542).

#### 4.5 John Paul II

Pope John Paul II argued that every intention to cause a patient's death was a morally bad option and that ANH ought to be given to anyone in need of ANH:

Moral and Pastoral Considerations, rightly emphasizes that the omission of nutrition and hydration intended to cause a patient's death must be rejected and that, while giving careful consideration to all the factors involved, the presumption should be in favor of providing medically assisted nutrition and hydration to all patients who need them. To blur this distinction is to introduce a source of countless injustices and much additional anguish, affecting both those already suffering from ill health or the deterioration which comes with age, and their loved ones (John Paul II, 1998, *Ad limina* address to the bishops of California, Nevada and Hawaii).

Here the pope makes a distinction between *ordinary means of preserving life such as feeding, hydration and normal medical care* from *medical procedures that may be burdensome, dangerous or disproportionate*. ANH ought never to be omitted with the intention of causing death, and the pope presumes that one ought to be favorable to provide medically ANH to all patients in need. The pope thus establishes a *presumption* in favor of use; however, strictly speaking, he does not require ANH in every case. There is not an agreement among scholars about what is meant by this presumption: is it a conditioned obligation, and if conditioned to what extent is it conditioned, and if it is an obliging duty, how does that fit in with the traditional authoritative teaching. There seems to be a consensus not to apply the strictest interpretation of this statement and view it in the perspective of compassionate care (Cahill, 2006, 130-131).

John Paul II addressed physicians invited by the Pontifical Academy for Life on 20 March 2004 to discuss care of PVS patients:

The sick person in a vegetative state, awaiting recovery or a natural end, still has the right to basic health care (nutrition, hydration, cleanliness, warmth, etc.), and to the prevention of complications related to his confinement to bed. He also has the right to appropriate rehabilitative care and to be monitored for clinical signs of eventual recovery.

I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.

The obligation to provide the "normal care due to the sick in such cases" (Congregation for the Doctrine of the Faith, *Iura et Bona*, p. IV) includes, in fact, the use of nutrition and hydration (cf. Pontifical Council "Cor Unum", *Dans le Cadre*, 2, 4, 4; Pontifical Council for Pastoral Assistance to Health Care Workers, *Charter of Health Care Workers*, n. 120). The evaluation of probabilities, founded on waning hopes for recovery when the vegetative state is prolonged beyond a year, cannot ethically justify the cessation or interruption of minimal care for the patient, including nutrition and hydration. Death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission (John Paul II, 2004a, § 4).

First, the general purpose of the pope is to be underlined: in a health care system with huge bio-technical advances that is evolving rapidly the pope wants to protect a moral objectivity within the Western ethical relativity patterns that have become widespread today; he warns the faithful against a culture of death with a trend of

accepting euthanasia and disrespecting human life, a kind of paternalism, emerging from the society, deciding for the weak and infirm the value of their lives. However protecting the value of life during every second of one's lifetime does not equate to using a feeding tube on every stomach.

John Paul II settles that patients will always remain human beings with their dignity safeguarded. Every attempt to reduce a person's life to some of its qualities must be firmly discarded. All have the right to the basic care. This includes nutrition, hydration, rehabilitation, cleanliness, and warmth. The pope reasons that all proportionate care is morally mandatory, both to give and to receive. To nourish someone, and thus alleviate this person's suffering is indeed care giving results in better health and a life that is proportionate to the efforts invested in the care. For every patient for which this remains true ANH is therefore in principle morally mandatory (Degnan, 2008, 41).

ANH is *in principle* ordinary and proportionate. This means at least that there can be hypothetical cases when this is not true. There might be some cases for when this is usually not true and where ANH is not appropriate. There might even be a minority of standard cases where this principle does not apply, for example, when the mode of nutrition or hydration for some reason is too burdensome. The pope's important expression "in principle" can be interpreted in different ways. Two major interpretations are that the expression would be understood as the medieval Latin expression *in se*, as either 'in itself' or as 'generally'. If in principle means that it is in itself proportionate, then this implies that nourishing and hydrating are always good measures to still hunger and thirst. This does not mean that ANH is always proportionate to the overall pathological condition of the patient. If proportionate means generally, then this is even more vague and implies that ANH sometimes does not even fulfill the proximate end of nourishing and hydrating of the patient (Cataldo, 2008, 146-147).

The reasoning of the pope is challenging and it may appear that the pope advocates that it is something good to let patients remain in a vegetative state, albeit the possibility to regain consciousness is very unlikely. This might first induce false hopes in those who are well acquainted with the patient, letting them hope for a recovery that indeed is quite unlikely to happen. Then it may seem awkward to those near the patient who see the body

deteriorate over time without certainty what the cause of this deterioration might be; either caused by some effects of the normal aging process, or somehow owed to the ANH. Finally, a person's human life and metaphysical existential worth is an incommensurable good in itself; however, not necessarily the only good one has to consider. This may appear incomprehensible to a modern mind of thought. If rightly understood, the question would then be whether the church still can make some exceptions to this rule of the incommensurable good and allow a withdrawal of ANH (O'Rourke, 2008a, 171).

The pope makes an exception for those in which "the provision of nutrition and hydration would not be appropriate, either because they would not be metabolized adequately, or because their mode of delivery would be gravely burdensome" (May, 2008, 69). His teaching does not require that ANH must be maintained, but only so, when the benefits such assistance provides are present and no excessive burdens are imposed. However, since the vegetative state is a vague label that embraces a variety of states, prognoses are far from reliable, and the assumption that the patient is unresponsive or unable to feel pain is highly questionable. This is why the pope thinks that ANH ought to be morally mandatory for everybody in a vegetative state. Another factor is that the persons in a vegetative state, will not die immediately, if they are fed and hydrated artificially, but they will die if they are not fed and hydrated by someone else. Thus you might question the intention, and the intention might become doubtful if the ANH is withheld or withdrawn. However, when it is possible to ascertain that ANH does not succeed in providing nourishment to the patient, or the alleviation of his suffering, then it is not useful to accomplish its primary purpose, and can then rightly be discarded for a more suitable care.

The pope seems to argue that ANH permits not only the continuation of the biological life of the body; it does also alleviate sufferings for PVS patients. However, there are some methodological problems with this statement: It is possible that one will avoid the sufferings from starvation and dehydration, if the patient can feel hunger and thirst, which is not established and a question to explore further. Much scientific research and evidence state that the withdrawal or foregoing of ANH cannot be felt by the unconscious patients. A more open attitude questioning these facts from the papal discourse, while yet

taking these facts and research into consideration, would probably gain a wider acceptance and seems academically more suitable. Especially, when one states that there are inaccuracies in the cited academic literature, then it is wise to specify both quotes of the erring sources and to build one's own arguments for contending views with reasons and evidence. As this was not done in the papal statement, one gets the impression that the speech is quite unscientific, especially when dealing with such important issues. There are some cases where it seems that the patient deteriorates over the years, and if some of these changes may be resulting from the aging process, others seem to be more probably linked to the illness. If one would argue that ANH would always be morally mandatory, one would have at least to give some reasons the patient sometimes suffers deterioration along with the ANH treatment. Likewise, if one claims that the possibility of recovery is well documented and that the withdrawal of ANH is a source of considerable pain, despite what most scientists claim has to be well founded and proved. Otherwise, these claims risk not being taken seriously. Further, the papal speech would have been better off stressing that there is a distinction between what is ordinary in medical practice and what is ordinary in moral terms, and thus mandatory (Shannon, 2008, 906). Finally, the pope recognizes that families sometimes have to be helped by the society to face the economic burdens of ANH care. It would also have been worthwhile to point out that the intrinsic dignity of every patient is so great in itself that ANH does not need to be used if it is too burdensome, too costly or otherwise too complicated (Cahill, 2006, 130 from CCBI, 2004, 778).

With euthanasia one wants to stop the patient's suffering by ending the patient's life. Euthanasia by omission is in this context a choice to stop a life sustaining or extending treatment so that the person dies and suffers no more. The purpose is to end the suffering by ending the life. If withdrawal of ANH with PVS patients has this purpose of ending the suffering by ending the life, therefore, there is an act of euthanasia by omission. The text of John Paul II can be read as saying that every withdrawal of ANH is an act of euthanasia by omission. This might be seen as if the moral object of a human act would be determined by the physical result of an action. However, since a human person lives in this world with its limitations and is finite in one's capacities and possibilities, one has only a very personal



and narrow perspective on all that is happening in the world, not being able to judge any act in its totality, nor grasp all the circumstances and determinations of the act. It is quite impossible that an act would not have at least two different moral evaluations. There are other possibilities judging the withdrawal of ANH than euthanasia by omission. The text of John Paul II may include other purposes for an act of withdrawal of ANH: namely that it is too expensive, burdensome or futile. These purposes do not imply that an act of withdrawal is equal to an act of euthanasia. A narrower connotation of the act of withdrawal is not in line with the Catholic moral tradition, nor with the actual practice within the establishments recognized by the Catholic church, and does not even conform to other texts written or addressed by John Paul II (Boyle, 2008, 116-117).

Nourishment and hydrating are in themselves good and useful to conserve life. The pope states that ANH is more comfort care than medical care insofar as it preserves life and it is difficult to see why the pope does not state instead that it is a medical comfort care. There is not an opposition between medical care and comfort care: they are two aspects of the care bestowed upon patients. He states further that ANH in principle that is both not regarding other treatments than the treatment of ANH in itself and speaking generally and not in every case, ought to be given to PVS patients, even when the predictions are that they will never regain consciousness. In the particular case and occasionally or *per accidens* they may not be useful. This tradition, states Cataldo, allows the pope to assert consistently on the one hand that ANH is a natural and proportionate way to care for human beings, and on the other indicate that ANH is not morally obligatory in each case: There may be many reasons ANH is ethically disproportionate for a particular PVS patient, however being permanently unconscious is not one of them (2008, 156).

Garcia proposes that the pope's statement that ANH is nursing care and not a medical act could be understood as it is not a healing, therapeutic or disease-preventive act (2008, 125); however, if ANH do not have these properties, why would one continue to feed and hydrate somebody and if ANH has these properties, then the suggestion to clarify the statement is not valid.

Barry suggests there would be a definitional difference between medical treatments and basic care of ANH: medical treatments are directly, proximately and immediately aiming at preventing or healing clinically diagnosable conditions and the basic care is instead building up and supporting the normal life of the patient. The resources that sustain the natural functions of an organism do not treat a pathology. However, the inability to eat and drink normally without the aid of artificial procedures is a result of the pathology, and ANH is remedying just that. So it seems that there are no clear boundaries between medical treatments and basic care. The demarcation line is not settled by what is accomplished by a treatment, here nurturing and hydrating a body, which indeed matters; the reasons why the intervention is necessary, how it is accomplished and by whom it is accomplished are other important factors relevant to whether something is a medical treatment or a basic care and nevertheless all these aspects do not exhaustively determine the difference (McCormick, 2006, 381).

The supporters of the theory of *incommensurable goods* think that life is always a good and ought to be preserved in any situation unless death is inevitable, and they would not agree on this interpretation of the papal document and say that it should be read as forbidding the withdrawal of ANH until the time when death is imminent. Those who believe that the papal allocution reverses the Catholic tradition and no longer approves that there might be reliable diagnosis of permanent unresponsive unconsciousness would also object to this type of moral reasoning.

In the following address to the participants of the 19th International Conference of the Pontifical Council for Health Pastoral Care, on how to care for PVS patients, John Paul II repeated the traditional teaching with regard to the removal of life support:

True compassion, on the contrary, encourages every reasonable effort for the patient's recovery. At the same time, it helps draw the line when it is clear that no further treatment will serve this purpose.

The refusal of aggressive treatment is neither a rejection of the patient nor of his or her life. Indeed, the object of the decision on whether to begin or to continue a

treatment has nothing to do with the value of the patient's life, but rather with whether such medical intervention is beneficial for the patient.

The possible decision either not to start or to halt a treatment will be deemed ethically correct if the treatment is ineffective or obviously disproportionate to the aims of sustaining life or recovering health. Consequently, the decision to forego aggressive treatment is an expression of the respect that is due to the patient at every moment.

It is precisely this sense of loving respect that will help support patients to the very end. Every possible act and attention should be brought into play to lessen their suffering in the last part of their earthly existence and to encourage a life as peaceful as possible, which will dispose them to prepare their souls for the encounter with the heavenly Father. (John Paul II, 2004b, §4).

According to this statement, an intervention ought to be beneficial and the aim of sustaining life or recovering health should be proportionate to the burdens of the treatment. Sometimes, further treatment may not be necessary, however, the term of aggressive treatment is not determined, and the reader remains in doubt whether this sometimes includes ANH. Does ANH prevent the patient from dying of malnutrition and dehydration or is ANH an encumbrance to accept the limited conditions of the patient? Do relatives to a person in PVS feel that they are murdering the patient by withdrawal of ANH instead of accepting the limits of biological life and that God is greater than are our desiderata? How ought one to act upon the text from the pope?

#### 4.6 After John Paul II

In a response to certain questions of the United States Conference of Catholic Bishops the Sacred Congregation for the doctrine of the Faith replied as follows on August 1, (CDF, 2007):

**First question:** Is the administration of food and water (whether by natural or artificial means) to a patient in a “vegetative state” morally obligatory except when

they cannot be assimilated by the patient's body or cannot be administered to the patient without causing significant physical discomfort?

**Response:** Yes. The administration of food and water even by artificial means is, in principle, an ordinary and proportionate means of preserving life. It is therefore obligatory to the extent to which, and for as long as, it is shown to accomplish its proper finality, which is the hydration and nourishment of the patient. In this way suffering and death by starvation and dehydration are prevented.

**Second question:** When nutrition and hydration are being supplied by artificial means to a patient in a "permanent vegetative state", may they be discontinued when competent physicians judge with moral certainty that the patient will never recover consciousness?

**Response:** No. A patient in a "permanent vegetative state" is a person with fundamental human dignity and must, therefore, receive ordinary and proportionate care which includes, in principle, the administration of water and food even by artificial means.

These indications are quite clear and show that the official teaching of the church is that a feeding tube is a morally ordinary and thus an obligatory means for patients in PVS. It seems that ANH would always be a proportionate means to preserve life, abstractly speaking, not taking in consideration any of the circumstances or other illnesses involved and as long as ANH fulfills the end, that is, actually feeding and hydrating the patients (Coleman, McLean and Steadman, 2008, 51). The statement presupposes that health expenses are taken care of by the society and thus does not constitute an excessive economic burden if not prolonged over time; that ANH could be easily given on a regularly basis at home; and that the intention of caregivers employing ANH is not to cure the patient, but only to take care of them. These presuppositions are not often commonly shared by the persons involved in the decisions of ANH concerning PVS patients (Hardt and O'Rourke, 2007). This doctrinal teaching does not consider the patients general condition, and other illnesses like, for example, dementia from which the patient may be suffering. A medical decision must take these circumstances into consideration when

making any judgement of a patient. Church documents must be read strictly applying to the question answered, and in this case the question is only about patients in PVS. The latest research broadens the actual category of severe brain injury to encompass many other subcategories that once, in fact, only some years ago also in the academic literature, was usually PVS. Another question influencing the moral judgement of this text is which implications one can draw regarding the text's definition of death: is total brain death the only possible definition? Still another question is how then patients in coma ought to be treated and how one ought to judge this condition morally, a question to be further investigated. It seems that some scientists would propose a higher level destruction of the brain as an alternative definition (Smith, 2008, 11). It has to be clarified what the *significant* in significant physical discomfort means: how much discomfort is needed for these rare and exceptional circumstances? For example, how are the economic burdens and the inherent psychological difficulties related to the significance of physical pain, and what are their effects? Today, the economic factors are still important, when many people do not have health insurance or health care being able to give the required treatments in cases of VS. Others live "in very remote places or in situations of extreme poverty" (CDF, 2007, §4). A disproportionate amount of effort and resources are dedicated to a small segment of the population, without it being wanted or appropriate - do the patients need this intensive care - (Smith, 2008, 11) while preventive care for many people may not be given since the global health budget is too tiny. Hospitals and even Catholic health-care institutions are facing economic challenges that force them to cut deficit costs to be able to continue to offer a good care. Psychological difficulties are today both known and widespread. What does *in principle* mean in the two answers: *the administration of food and water is in principle a proportionate means of preserving life* and *in proportionate care which includes, in principle, the administration of food and water*? Lori and Rigali let *in principle* mean as a general rule and highlights that "providing assisted food and fluids may cease to be obligatory in particular circumstances" (2008). There are exceptions to this general rule. These exceptions emanate in the CDF commentary and concern patients in remote places or in situations of extreme poverty, which might make the administration of ANH impossible; when a patient is unable to assimilate food and liquids and ANH become futile; when ANH is excessively

burdensome for the patient, even if the burden for the patient is not necessarily a physical burden; when ANH causes significant physical discomfort, for example resulting from complications in the use of the means employed, e.g., infections or aspirations (Hardt and O'Rourke, 2007, 44). If moral certainty that the patient will never recover consciousness is not enough, when then can administration be useless and hopeless? Probably, the answer would be that it is when one makes the discernment to consider the general welfare of the patient instead of the particular benefit of nutrition and hydration contributing to a biological system or organ. A particular organ or biological system may today medically be maintained while not providing any significant therapeutic benefit to the patient (Shannon, 2008, 911-914). Nutrition and hydration might not be taken as literally as food and water, but rather in a more general, spiritual or metaphorical interpretation.

#### 4.7 Actual research

There have been several important discoveries in the last years. The understanding of how patients may recover consciousness and abilities of the human brain after severe brain damage has been seriously challenged and revised.

New ways of detecting and screening patients with neuroimaging lead to better diagnostics and prognostics. Patients showing little or no behavioral evidence of conscious awareness have unimagined cognitive capacities, and some patients having been for a long time in a disorder of consciousness and having shown limited responses to stimuli have demonstrated to have unsuspected capacities for recovery and can be able both to communicate and to learn some knowledge about their surroundings. These capacities may reemerge later on by direct stimulation and interventions or spontaneously.

The outcome from a post coma unresponsiveness state is varied: the outcome can be a good recovery, where the patients can return to normal activities of occupational and social interaction with not more than some minor physical or mental deficits.

Patients who recover from a vegetative state give at first very small almost imperceptible signs of consciousness which appear gradually, e.g. making deliberate movements without being able to express oneself. At this point, the patients have entered the minimally conscious state (MCS). Examining magnetic resonance imaging images

helps physicians to predict whether the patient will emerge or not, depending which parts of the brain are damaged. Functional neuroimaging, using positron-emission tomography, shows the metabolic activity of the brain. Furthermore, brain network and links between the cortices themselves and between the cortices and the thalamus seem of special importance for the recovery of consciousness. However, it seems like the network for pain perception does not work in vegetative patients and thus that their pain perception is different from that of normal people (Laureys, 2007, 34-35). There is a complementary and simpler way of detecting these differences in state; it has to be shown if they can be made as sure as neuroimaging in expanding the time span survey. However, there is a straightforward compatibility. The EEG analysis can detect many patients that formerly were classified as vegetative state patients and now are classified as minimally conscious state or locked in state patients. The flexibility, the cost-effectiveness, the ease-of-use of EEG, and the fact that high-density EEG recordings can now be performed very quickly, make EEG good alternative to other neuroimaging tools (Michel and Murray, 2012, 371, 382).

In 2002, Giacino et al. published the operational criteria for MCS, separating some patients that usually were described as PVS and however showing different behavioral signs of awareness and a very poor intermittent communication. Objective measures to state patients emerging from MCS were also set up like those of functional communication that is not an inconsistent and unreliable one, and a functional use of objects (Laureys and Schiff, 2012, 479).

Patients in minimally conscious state must be distinguished from patients in a vegetative state, and this discernment is often difficult to make. Patients in a minimally conscious state can recover from their state many years after they entered this condition. The state of the brain is evolving because of the injury and because of the varied care offered the patient; e.g., when the patient is transferred from a hospital to a caring residence. The patients can change to MCS, while in chronic care, and then it is important to note the difference of state and in due time not label it a permanent vegetative state. Because the MCS state is episodic, it is easy to make mistakes. Families might reproduce signs of the episodic communications. Fins estimates that so many as a third of the

patients diagnosed with PVS may be in a MCS. Greater precision in discussions is now recommended by him. He suggests that the terms of persistent and permanent will be replaced with labels regarding its cause; thus, traumatic and non-traumatic (anoxic) vegetative state and the length of its duration. Diagnostic errors might prolong a family's false hopes to regain contact with a patient in PVS or oversee the potential to recuperate a normal life with a patient in MCS (2008, 18-19).

The outcome from a post coma unresponsiveness state can be a moderate disability, where the patients after recovery are independent and can assume most of their former daily personal and self-care activities, however not in their former occupational and social activities; and the outcome can be a severe disability, where the patients cannot assume their former personal, social and occupational activities with limited possibilities to express their feelings, conform to normal ways of behavior, and communicate with others (AAN, 1995, 1015). Thus, science understands brain injuries in another way today than it did earlier. This can be pictured with the following image:

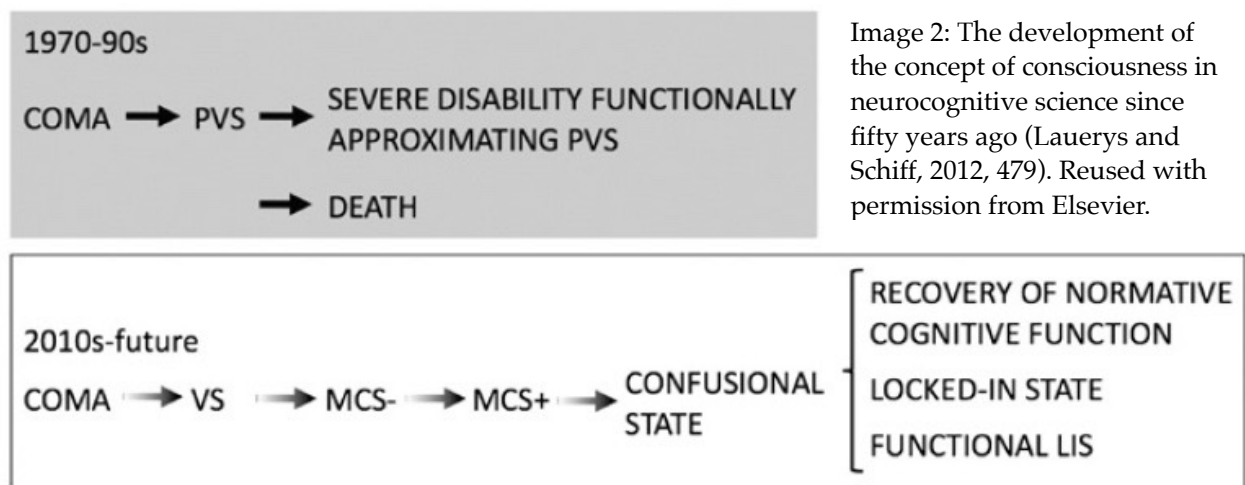


Image 2: The development of the concept of consciousness in neurocognitive science since fifty years ago (Lauerys and Schiff, 2012, 479). Reused with permission from Elsevier.

The spectrum of states of those affected by disorder of consciousness is now more graded and detailed, based on quantitative behavioral assessments e.g. with the recommended Coma Recovery Scale - Revised (Giacino & Kalmar, 2004, 1-16), and functional neuroimaging methods. While some of the vegetative state patients will die from this vegetative state of consciousness, the last years of scientific research have proven that many VS patients evolve to MCS patients. The graph shows that patients who previously were labeled to be in a vegetative state or in an unresponsive wakefulness state, now appertains to a minimally conscious state, either showing low-level non-reflex



movements like visual pursuit, localization of pain or appropriate smiling to emotional stimuli (MCS-) or high-level behavioral responses with fluctuating command following or specific responses to linguistic content (MCS+).

Some authors have not been willing to make these distinctions, perhaps due to the difficulty deciding in which category a patient ought to be put, and this is why a certain confusion has reigned within the scientific field. It is now well established that the bedside examination of consciousness in severely brain damage patients does not at all capture the real state of the patients, especially as the movements of the patients can be very tiny, appearing rather seldom and the patients are easily exhausted even with little efforts. This has led to and is still leading to diagnostic errors, and the verifications show that about 40% of the patients have a wrong diagnose with the bedside examination. Other added illnesses can make it even harder to diagnose a patient successfully. There is even more confusion when also locked-in syndrome patients are also considered.

The following descriptions and comparisons between different states of consciousness will make it clearer how the boundaries between them are on their way to be established.

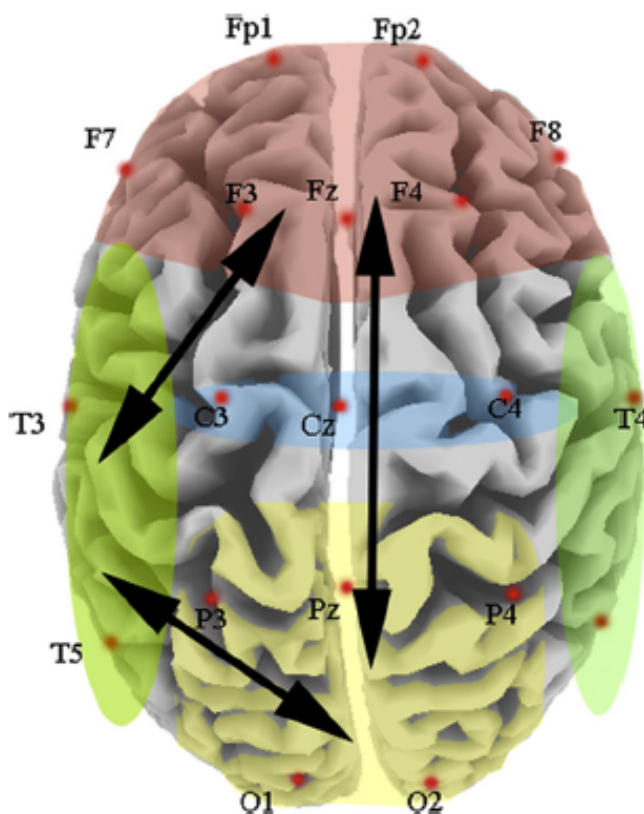


Image 3:  
There is probably an important difference between patients with a severe neurocognitive disorder, like the patients in a vegetative state or in coma and patients in a minimally conscious state regarding the synchrony between anterior and retrolandic regions. The image is showing areas with significant differences in number of functional connections between VS and MCS patients using plain coherence analysis (Leon-Carrion, 2012, 24). Reused with permission granted by the authors.

Some patients awakening from their coma may show no behavioral sign of awareness (VS) or remain unable to communicate (MCS). There are important differences in conscious perception and possible outcome between VS and MCS. It has been shown that for MCS patients cerebral integrative processes remained in a way unknown for the VS patients. It is a challenge to take care of these patients; however, new technological advances in neuroimaging may facilitate making diagnoses, prognoses and treatments optionally including drugs for these disorders of consciousness. It seems that the synchrony between anterior and retrolandic regions is essential to awareness, and that a functioning frontal lobe is a surrogate marker for preserved consciousness.

The criteria for MCS are an intermittent ability to interact normally with others; scarce or inconsistent behavioral responses to visual, acoustic, tactile or verbal stimuli; scarce or inconsistent verbal comprehension or expression; an intermittent state of alertness compatible with sleep-and-wake cycles; maintenance of autonomic functions by oneself alone or with medical care or with nursing care; inconsistent eye-tracking of objects and people; scarce or inconsistent response to familiar emotional stimuli (Leon-Carrion, 2012, 24).

Neurological imagery indications of awareness and preserved consciousness might be a possible way to differentiate MCS patients from patients with a preserved state of alertness and better levels of consciousness, that is, patients with severe neurocognitive disorder (SND) (Leon-Carrion et al., 2012, 22). The criteria for SND are an ability to interact with others; consistent behavioral response to visual, acoustic, tactile or verbal stimuli; preserved state of alertness and sleep-and-wake cycles; notable decline from prior level of functioning; difficulty with work, study or family life; severe deterioration of memory structures and memory processes; severe deterioration of other neurocognitive functions, like attention, language, motor abilities, recognition, imagery, and executive functioning; anatomical or functional neuroimaging should demonstrate brain abnormalities; behavioral and cognitive disturbances will not meet the criteria for delirium, or amnesic disorder; behavioral–cognitive impairment is visible from the acute phase (Leon-Carrion, 2012, 25).

Recent research discovers that between ten to twenty-five percent of those who earlier were diagnosed with PVS actually are MCS patients, able to generate EEG responses to two commands involving motor imagery of playing tennis or visiting the rooms of one's house, although the patients were otherwise behaviorally unresponsive. Most researchers have interpreted these published results suggesting that patients in the vegetative state are wrongly diagnosed and ought to be recognized to be MCS patients (Boly et al., 2007 in Laurels and Schiff, 2012, 482). However, this is not to say that those who are unable to initiate this neuroimaged communication have no consciousness, while the absence of brain activity can have many possible causes, from test defaults, disturbing elements, spontaneous fluctuations and medication related questions. Moreover, these results say nothing about the possibility for these patients to regain a reliable and consistent communication. Overgaard and Overgaard suggest that the explanation rather is that vegetative state and minimally conscious state patients have different levels of consciousness, that is, different levels of cognitive and communicative abilities. A new classification system is necessary (2011, 2052-2053). Clinical misclassifications remain one of the big problems of this area. Low-frequency power, electroencephalography complexity, and information exchange are the most reliable signatures of which conscious state the patients belong to. To combine different methods will increase the results in discriminating whether a patient is in a vegetative state or not (Sitt et al., 2014, 2258, 2264).

Comparing MCS patients with normal subjects' responses the MCS patients give unreliable responses, their neuronal responses are similarly unstable, their quality of overall network responses is inferior to normal subjects responses and they have also an inferior general resting metabolism, albeit passive language stimulation may show a large-scale cerebral network response despite low rates of global metabolism. Resting metabolism and thalamus regulation of anterior forebrain activity seem to be major pattern in increasing neuronal activity and making consciousness possible. Changes in internal brain dynamics may correspond to conscious awareness and higher level brain function. Patients emerging from MCS enter a confusional state below the normative neuropsychological function and wherefrom further recovery depends on in what measure the motor functions are reestablished. Cognitive function with nearly no motor

output is called a locked-in state and if there is no motor output a functional locked-in state: here it is only the communication through neuroimaging techniques that has the possibility to show that there is a consistent and reliable communication, that is, the communication manifests itself only through direct brain signaling and not through speech or gestures (Laureys & Schiff, 2012, 479, 484-485, 487-488).

In the last two or three years there some researchers contest the possibility to make these distinctions only relying on the investigations performed so far. It is a general presupposition that VS can be distinguished from MCS; however, the differentiation between VS and MCS is not easy to make. Factors involved in making the distinction are the evaluator's interpretation between the purposeless and involuntary behaviors in VS and the purposeful and voluntary behaviors in MCS (Kotchoubey et al., 2005 in Liberati et al., 2014). Purposeful behaviors, like responding to questions, reaching objects, touching and holding objects realizing the shape or the size of that object, eye gestures following what is happening or fixing for a while on someone or something in response to stimuli and specific behaviors, the capacity to follow simple commands, or to respond by words and by gestures is thought to characterize the MCS and differentiate it from VS (Liberati et al., 2014). These features give good impressions of the development of consciousness; however, there are no clear frontiers separating the two states of consciousness and many factors can influence the clinical judgments: the evaluators are more or less trained to evaluate these states of consciousness, the patients are treated differently from a medical and a physical point of view and the patients' ability to make movements is often limited, inconsistent and easily exhausted (Gosseries et al., 2011 in Liberati et al., 2014).

There are four different main categories of experiments to stimulate responses from patients with a consciousness disorder: stimulus-independent physiological and neurophysiological assessments; stimulus-dependent behavioral assessments; stimulus-dependent neurophysiological assessments, using sensory stimuli; and stimulus-dependent neurophysiological assessments, using meaningful stimuli.

Within the first main category of experiments, the stimulus-independent physiological and neurophysiological assessments, there are measurements taken when the patient is at rest, like electroencephalography (EEG), where a higher complexity

indicates a more developed state of consciousness and positron emission tomography (PET) that evidences the relationship between electric brain activity and cerebral metabolism, existing in MCS and not existing with VS. The experiments indicate a correlation between electric brain activation and levels of cognition, but do not clearly discriminate between VS and MCS. The levels of activation are clearly lower for patients with a consciousness disorder. The indices however do not clearly enough separate between VS and MCS in some reports, while they are differentiated in other reports, sometime by the same research teams. Another type of experiment is assessment of whether the patients are wake or asleep by studying wake-sleep cycles. The researchers have not found that sleep-wake cycles are different between a patient in VS and in MCS.

Within the second main group of experiments, stimulus-dependent behavioral assessments, there are experiments assessing the ability of visual pursuit, that is, whether the patient can follow a movement with his or her eyes. It is difficult to say whether visual pursuit is a result of voluntary or reflexive reactions from the patient, and this depends much on the judgement of the examiner and the tools of assessment. There has been, according to Liberati et al., only one such experiment, and it states a generally low ability of visual pursuit, where even MCS patients can be unable to follow the movements with their eyes (2014, 6). Electrophysiological assessments and neurological images have been developed to accompany the behavioral evaluation of disorders of consciousness.

Within the third main category of experiments, stimulus-dependent neurophysiological assessments, using sensory stimuli, there are partly auditory and visual stimulation and partly somatosensory, nociceptive and transcranial magnetic stimulation.

Moral theologians have to follow these advances to make proper moral judgements. These discoveries urge moral theologians who consider medical ethics to reframe also the moral guidelines how to act in a good reflected way in proportion to certain particular situations. In the light of these new discoveries, older statements from the magisterium have to be understood and reevaluated. This is in harmony with the recent teachings of the church's magisterium, which "has closely followed the progress of medicine" (CDF, 2007). There is no longer only a difference in duration of the vegetative state, but a differentiation

in states of brain injury damage. This affects the moral judgement of these matters. This gives motives for a further reflection; whereto this essay wants to be a part. Before it is time to begin the ethical analysis of this thesis question in general and the moral case, the thesis examines in particular; it can help in a more systematic way to summarize the philosophical insights and historical events that now have been described.

## 5. What it is about: Catholics, Nutrition and Hydration

The chronological overview describes the development of how the Western tradition has reflected on nutrition and hydration for persons in a critical situation. This chapter will give a comprehensive systematic review and analysis of the most important and the most relevant concepts. Some moral questions will open the ethical discussion that will follow in the latter part of this thesis.

### 5.1 Defining consciousness

Consciousness has many different meanings, which affect each other but are not synonymous with each other. Scholars are not at all in agreement on the question of what consciousness is, and it is wise to keep in mind that the consciousness remains an unsolved, and complex, mystery. An attempt will be made here to clarify something what is meant by the term in this context.

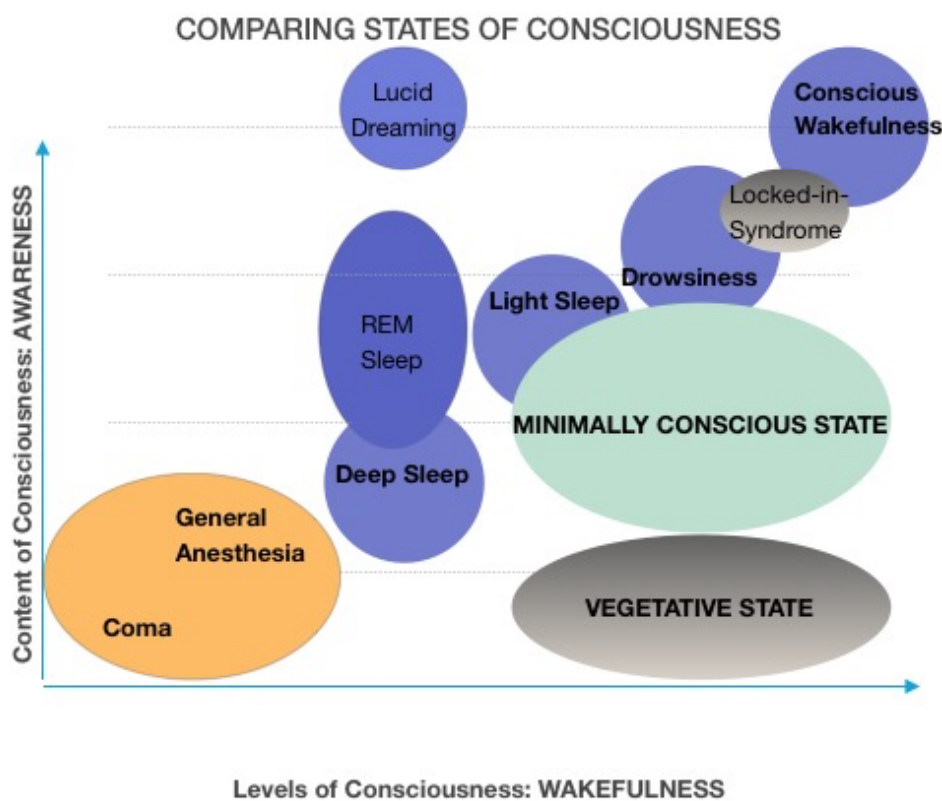


Image 4 :  
Comparing states of Consciousness  
The image is based on an image in Laureys, Steven. *Eyes open, Brain shut*, in *Scientific American*, May 2007, 35.

The two main components of human consciousness that normally function are wakefulness and awareness. These features vary depending on the level of consciousness a human being has. They are not functioning in a coma, and they become disassociated in the vegetative state, so that wakefulness is manifested through sleep-wake cycles, but awareness through thoughts and feelings does not function (Laureys, 2007, 32). Conscious human beings sense the world they live in and respond to the world. They exist and understand themselves as being a part of the world surrounding them and as being in a relation to themselves. There have been suggestions on where in the brain the consciousness would be located, e.g. in the prefrontal cortex, or about what consciousness would consist, that consciousness would be linked to the microscopic structure of the cosmic space and time, described like waves of quantum particles collapsing (Hamerhoff and Penrose, 2013, 74); however, no attempt has decisively solved the mystery, no attempt has attracted everyone's attention, and no attempt has received everyone's approval. There seems to be a temptation to explain consciousness as a feature placed in a specific area of the brain. Consciousness is a sum exceeding the combined parts of the brain. Perceptions, events and factors from the outside affect one's consciousness. Consciousness is here a general term, it is both nowhere and everywhere. Consciousness is a feature of the whole brain: the sole fact that a particular area is more active than others, does not imply conscious activity (Farisco, 2015). Consciousness can furthermore be a very personal feature, depending on subjective perceptions.

## 5.2 Coma

A coma lasts usually only some weeks and is the initial state of a severe brain-injury. Comatose patients have their eyes closed. They are unresponsive and unable to arouse. Comatose patients can have different outcomes, from brain death (brain-stem and higher brain functions) to full recovery. Comatose patients can become patients in a vegetative state (Fins, 2008, 16).



### 5.3 The vegetative state

VS means that the patient, a human being, does not have any higher brain functions and complete or partial hypothalamic and brain stem functions left. VS patients' biological life remains normally intact; VS patients can breathe normally and are not dependent on ventilator support, they can digest what they take in, and the stable bodily state of equilibrium, or homeostasis is working. Gag, swallowing, and cough reflexes and the functions of digesting and waste elimination are thus maintained, however, the function of eating is also lost because of a lack of coordination between chewing and swallowing. For some though, this is not the case; their brain stem is damaged and they will need help to sustain the mentioned functions. They are, as far as we know, unaware of themselves and of their surroundings and unable to interact with other people. They do have sleep-wake cycles, thus, their eyes are often open and they can manage several reflex activities, but they do not visually track on anything and have no meaningful response to a stimulus. Grunts and groans may also be emitted, but they have no meaningful significance. The power to think, choose, love, and relate to others is lost.

The VS patient is often caused by an acute incident. Patients who are in a vegetative state may have a startle reflex, a non-intentional behavior originating from the brain-stem. The patient shows sleep-and-wake cycles with eye-openness; the patient has sweeping movements of the eyes and conserved reflexes; e.g., to seize, suck, and bite, conserved brain stem reflexes. A person in a vegetative state can show signs of fever and sweat, and can shed tears and react to noises. A vegetative state can be labeled persistent when it lasts more than one month. When the initial injury is oxygen deprivation or anoxia, from for example a cardiac arrest or a drowning accident, or other non-traumatic injuries caused by e.g. surgical complications, brain infarction, infections, poisoning or metabolic conditions, the persistent vegetative state was labeled a permanent vegetative state when it endures more than six months. When the initial injury is a traumatic brain injury, from e.g., a motor vehicle accident or a fall, the persistent vegetative state was labeled a permanent vegetative state when it endures more than twelve months. The difference of time between traumatic and non-traumatic injuries still corresponds to the likelihood of recovery. Recovery of consciousness is indeed unlikely after twelve months for patients having had

a traumatic incident, and after six months for patients with a non-traumatic incident. A VS patient's average survival with ANH is between two and five years. The cause of death is often an infection in the lungs or in the urinary tract, respiratory failure, or a sudden unknown cause (Panicola, 2001a, 14). Please note that there is a considerable difference between the state of coma, from which patients often recover and the unconsciousness associated with VS, from which a resurgence is quite unusual exceeding the time limits indicated above.

The definition that has most informed clinical decisions and bioethical discussion is the consensus statement of the Multi-Society Task Force on PVS 1994:

The vegetative state is a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain-stem autonomic functions. The condition may be transient, marking a stage in the recovery from severe acute or chronic brain damage, or permanent, as a consequence of the failure to recover from such injuries. The vegetative state can also occur as a result of the relentless progression of degenerative or metabolic neurologic diseases or from developmental malformations of the nervous system. The vegetative state can be diagnosed according to the following criteria: (1) no evidence of awareness of self or environment and an inability to interact with others; (2) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; (3) no evidence of language comprehension or expression; (4) intermittent wakefulness manifested by the presence of sleep-wake cycles; (5) sufficiently preserved hypothalamic and brain-stem autonomic functions to permit survival with medical and nursing care; (6) bowel and bladder incontinence; and (7) variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes (MSTF, 1994a, 1500).

The members of the scientific community do not agree on whether the vegetative state really is unconscious or not, mainly because there are researchers claiming that the

vegetative patients can feel pain and that this fact is empirically supported. Dr. Alan Shewmon from the University of California in Los Angeles (UCLA), argues that sensory receptors for painful stimuli, or nociceptors have their end not in cortex but in thalamus, which remains intact by PVS patients. The cortex's role in pain perception is merely modulatory. And even if cortex is involved, some studies show that cortex may be receiving the signals of nociceptors. The PVS patients therefore can feel pain. The fact that these patients can feel pain would contradict the unconsciousness of the vegetative state (Shewmon, 2004a, 345 in Degnan, 2008, 43).

Those who argue differently say that this phenomenon comes only from either brain-stem or spinal reflexes. MSTF is advocating that VS patients cannot feel pain, saying that motor movements, eye movements and facial expressions are only responding in a stereotyped pattern to stimuli indicating reflexes and no voluntary acts. The glucose metabolism of VS patients is comparable to patients in general anesthesia indicating unconsciousness. VS patients have severe lesions of the brain.

Shewmon argues that the widespread acceptance among medical authorities to describe patients in a vegetative state as unconscious and unable to feel pain is based on negative arguments, where "patients with diffuse cortical destruction do not manifest clinical signs of awareness of self or environment. But, there was no positive evidence that such patients are not inwardly conscious." (Shewmon, 1997, 59-60 in May, 2008, 63).

Degnan claims that MSTF does not give any anatomical evidence that the cortical structure is not involved. Maybe the cortical structure is involved, or maybe the patient can feel pain, but unable to communicate his or her feelings. Shewmon does ask the question whether what one usually has called PVS in reality might be a super-locked-in state, a state where one is conscious and unable to communicate with one's environment through external manifestations (1997, 59-60). MSTF does not provide any evidence that there are no event-related reactions by VS patients. MSTF does not explain the variation of glucose metabolism between patients, nor that a low glucose metabolism makes it impossible to wake up. MSTF does not prove that lesions imply that there is no cortical activity, while new research indicates there are, and even if there are not, there is evidence showing that cortical activity is unnecessary for awareness of environment and self,

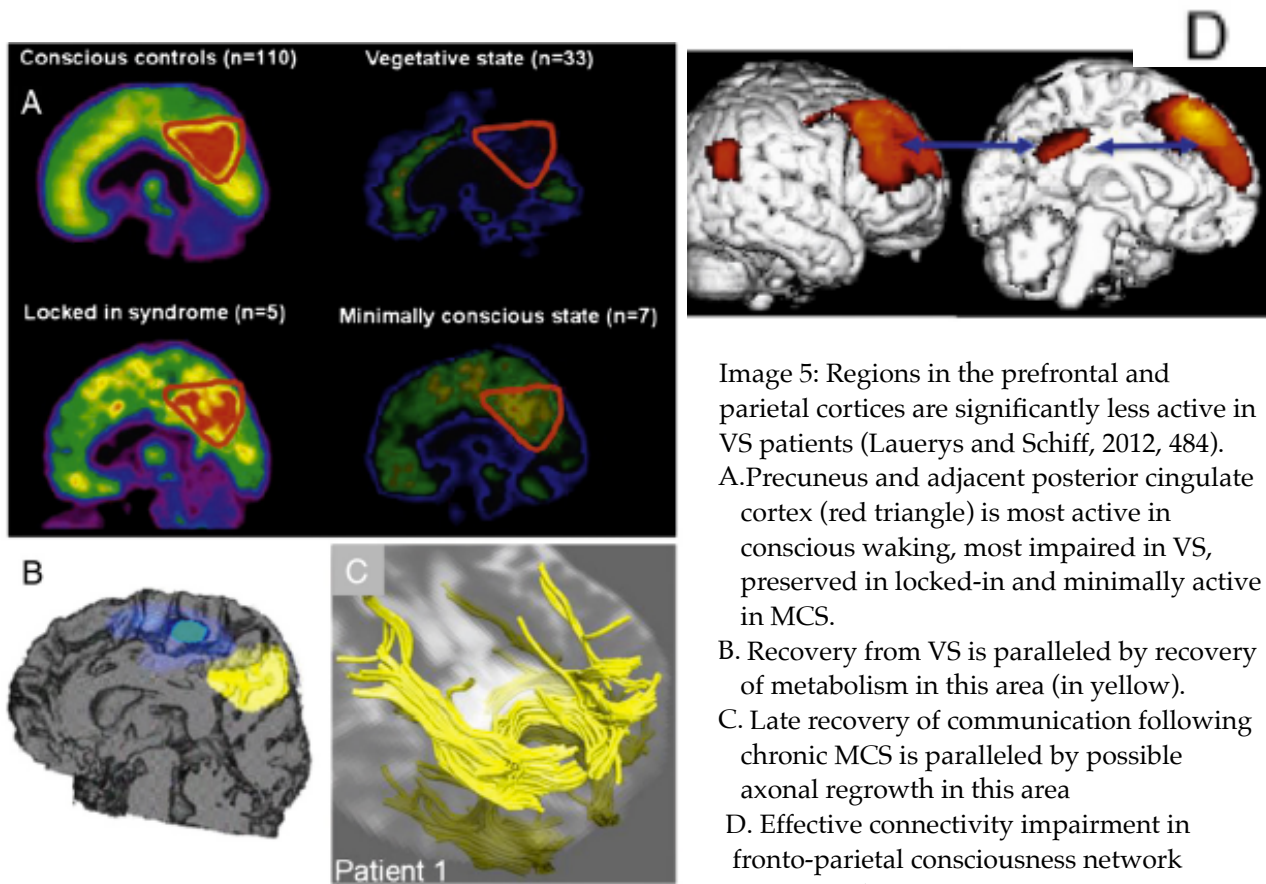


Image 5: Regions in the prefrontal and parietal cortices are significantly less active in VS patients (Lauerys and Schiff, 2012, 484).  
 A. Precuneus and adjacent posterior cingulate cortex (red triangle) is most active in conscious waking, most impaired in VS, preserved in locked-in and minimally active in MCS.  
 B. Recovery from VS is paralleled by recovery of metabolism in this area (in yellow).  
 C. Late recovery of communication following chronic MCS is paralleled by possible axonal regrowth in this area  
 D. Effective connectivity impairment in fronto-parietal consciousness network measured at rest.  
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especially with a child after a traumatic injury.

Some children may become more playful after an intervention. All these features lead to a strong case in favor of ascribing pain experience to VS patients who are roaming, grimacing and acting with a withdrawal behavior from stimuli (Degnan, 2008, 42-43).

All doctors will not be convinced by these facts: when sorting out traumatic injuries from non-traumatic injuries, children from adults and more specifically when classifying different types of not fully conscious mental states, it is possible that those who still will be labeled a vegetative state, will not feel any pain, nor have any chance to wake up and only be able to survive with ANH. Injuries do differ between patients who have had severe brain damage, those who have developed a VS from degenerative and metabolic disorders, because of medication, infections, other illnesses, or decreased fluid and nutritional intake, and finally those new-born babies who have never been in another state than in VS, owed to severe developmental malformations of the nervous system (AAN, 1995, 1017).

It will here be argued that some uncertainty is resulting from a too large definition of the vegetative state that up until recently has included not only vegetative patients, but also minimal conscious patients. Traditionally VS patients have been observed failing to respond externally to communicative, sensitive or noxious stimulation. Some experiments indicate that this is not true, and that there is a response to noxious stimulation. However, if we keep the definition of vegetative state as it has been, the reason for these contradicting facts may be due to that the patients are in a minimally conscious state and not in a vegetative state. Then, the MSTF argumentation would still be valid, but to a more restrictive number of patients. Most persons believe that MCS patients can feel pain. The opinions are more divided concerning VS patients, and this can be resulting from different perspectives in judging the patients. Most medical doctors do not believe that VS patients can feel pain; however, "paramedical professionals, religious participants, and older caregivers reported more often that VS patients may experience pain" (Demertzi et al., 2009, 336). Continuous discussions, research, and evaluations are important due to the medical development and the technical and ethical complexity of the issues.

#### 5.4 Minimally conscious state

There is an important argument why the rather firm statements of CDF need to be reconsidered, not altered, although put in perspective with the recent knowledge concerning newly defined brain states: One ought to give a moral evaluation of the MCS patients and see whether this evaluation also affects the moral evaluation of VS patients.

The minimally conscious state (from MCS+ to MCS-) is a state that requires a careful clinical evaluation and more scientific research before being completely affirmed. The MCS was defined in 2002.

The patients are conscious in MCS. The MCS patients are aware of themselves and of the environment in a shifting degree. In the minimally conscious state, volitional response to stimuli as signs of consciousness is seen reproducible; however, not consistently. Also, in the minimally conscious state can observe the volitional ability to follow the (simple) calls; gestures or verbally mediated responses by yes or no, or single verbalization with occasional adequate words, without that these stimuli of words that

permit functional communication; targeted and volitional discriminative and affective behavior, like crying or laughing that could be considered adequate to the presented stimuli; or sustained visual pursuit movements. They may communicate through words, phrases and gestures. They might remember something, be attentive to someone, or have an intention with something. However, these abilities can go back and forth during the MCS. "The inability to reproduce telltale signs of awareness is part of the biology of MCS and an expected and confounding part of the clinical picture"(Fins, 2008, 17).

Until now, there are no tools that can give a sufficient specific image to discern whether we have a case of a vegetative state or a case of minimally conscious state before our eyes. However, you can progress from a persistent vegetative state to a minimally conscious state. When you are in a non-behavioral MCS, you are able to respond to questions about; e.g., home and usual activities with linguistically ambiguous phrases of normal language and with spatial brain networks. These networks retain the potential of activation. The recovery from MCS is possible, and rarely a dramatic recovery may occur several years after the injury. Neurological images and research indicate that patients with severe brain injury may recover after a considerable amount of time and that probably they harbor residual functional capacity. Brain stimulation might be of a help in these recoveries.

The MCS patients who can consistently speak with others and otherwise communicate with their environment have recovered from their MCS. Wallis, injured in a traumatic motor vehicle accident, recovered after nineteen years from what is now believed to be a MCS that earlier was labelled a vegetative state. Herbert was in a presumed vegetative state for nine years, before a physiatrist gave him psychoactive drugs and he spontaneously regained fluent speech. Both patients are conjectured having reached MCS rapidly after their coma, thus retaining the potential of further recovery (Fins, 2008, 15-17). It seems important to respect this rare chance of recovery to life for MCS patients, at least when it is not too burdensome for the patient.

## 5.5 Nutrition: in the Bible and elsewhere

Feeding the hungry is an ideal in the gospel and a part of the teaching of Jesus and of the life he lived in company with the poor sinners. Blessed are those who have aided those in need. Eating and drinking is a part of the Christian life and devotion. It is a sign of inclusion and belonging to a certain group. Feeding and hydrating are essentially nourishment for the human person that can be amplified with cultural, social, and religious values and with which the person can be psychologically enriched. There is a challenge to humanize eating and drinking in hospitals, like there are many other aspects of personal care needing to be humanized, making these occasions as normal as possible for those who are cared for.

Nutrition is the result of alimentation, where the body assumes substances necessary for its metabolism and its daily functions. Artificial nutrition is a therapeutic procedure or a medical means through which the body is assured the substances necessary for survival, when the body is unable to take in nutrition the natural way. The common procedure of placing a relatively stable feeding tube would generally not imply a heavy burden on the patient. The burdens of medical care can affect the pursuit of goods that are important in human life: economic, physiological burdens of extreme pain, psychological burdens of losing life or subjective fears, like that of a shy woman being treated by a man, social burdens in communicating and living with others and spiritual burdens in the relationship with God (Ashley, 2006, 187).

Morally there are several relevant aspects of eating and drinking: there is a corporeal satisfaction including a need to be satisfied and there is a spiritual sharing of communion with one another. The food and the drink serve the purpose of conserving, building and developing the body and maintaining life (Cataldo, 2008, 145).

When a person is in a VS, then the patient cannot eat and drink without help. A tube feeding of any sort is a medical intervention which should be done professionally. Inserting the tube, monitoring it and prescribing dietary supplements are all activities that require a physician's medical knowledge, while the actual feeding could be handled by nurses, family and proxies. Artificial feeding where someone is fed, might not be a meal properly defined. It seems there has to be more than a material, unconscious and passive

participation to a meal to fulfill the hearts participating in a symbolic meal. The human being has his or her dignity in that he or she is a human being, not in that he or she is fed. One could argue that this is a precious and valuable matter for a human being to be preserved in its biological life, and indeed it is. One might however appreciate other forms of life that will influence how much one will appreciate an artificial preservation of biological life. The very question is: are the efforts of feeding, whether a medical treatment or just a variant of one's normally eating, proportionate to the goals of life?

When the Pontifical Council *Cor Unum* labels ANH a minimal measure (*Cor unum*, 1981, 4-5), then it is true that alimentation is a normal and customarily procedure to maintain life; there is however, an extraordinary circumstance for the VS patient, when it is established that the person will be unable to consume anything alone. That would make these cases different from that of helpless children or other severely damaged patients who hopefully will be able to eat and drink one day without any exterior help. This is also the reason why withdrawing ANH from a VS patient is to accept that this patient will no longer be able to survive alone, and not primarily a wish to put an end to this patient's life. Often, there is no such wish at all. Everyone would like the patient to survive. There is no definition available how minimal ANH is, that is, in which circumstances it must be employed. To say that it has to be used in all situations, would be to impose a therapeutic means on a patient who would find it repugnant, or to a patient where the consequences of the reception might be more burdensome than helpful. Another argument stating that routine measures should be used whenever available is equivalent to considering the effects of a successful or unsuccessful treatment and basing one's decision on this parameter rather than to investigating the effects on the patient and on those who have the responsibility of caring for the patient and then determining the treatment's effects according to this more integral view (Shannon, 2008, 904).

## 5.6 Artificial Nutrition and Hydration

For patients who are unable to swallow, due to invasive tumors, weakness, or neurological disorders like VS, feeding through a tube has been the standard delivery of nutrition. The nasogastric tube is the easiest way to achieve this. A tube is inserted



through the nose and down the throat into the stomach. A liquid food formula is given through the tube continuously at a slow rate or several times a day with a larger dose. Patients with nasogastric tubes have a higher risk of pneumonia which can significantly lower their survival rate. Nasogastric tubes can also be easily pulled out, causing distress to both the patient and their loved ones.

A gastrostomy tube is one that inserted directly into the stomach by a surgical procedure. A percutaneous-endoscopic gastrostomy, or PEG, tube, is done endoscopically and is less invasive. With either of these tubes there is less risk of the patient pulling the tube out. There is still the risk of pneumonia, however. Just like the nasogastric tube, there is little evidence that feeding through a gastrostomy tube will increase the health or life expectancy of terminally ill patients.

If a patient can no longer drink fluids or isn't drinking what his caregivers think is enough fluid, the caregiver may be tempted to ask for intravenous fluid. Fluids can be delivered through a small needle that is inserted in a vein and hooked up to tubing. Studies have shown that administering fluids to a terminally ill patient at the end of life offers little, if any, benefit. Risks include infection at the insertion site or in the blood, and fluid overload resulting in swelling or even breathing problems in more severe cases (Morrow, 2014, slightly adapted text).

In a conscious patient there might be distress, disorientation, and deterioration caused by a new procedure of ANH. There are risks of infection and of concentrating more on the tube performance than of the health of the person treated (Valiquette, 2008, 558, 560). There are contraindications to placing a tube when the nutrition or hydration cannot be absorbed by the patient, which occurs for example, when a patient is dying of a cancer in the intestines; or patients suffering from severe kidney, heart or liver failure, when the metabolism process is too weak to be able to support ANH. In the terminal phase of different cancer forms, not eating or drinking is a part of the dying process and inserting a feeding tube would provoke complications and pain. Complications are mostly minor troubles, rather rare ones, and consist in aspiration, when saliva and some nutrition come into the lungs, which could provoke edema, diarrhea or other sorts of problems. Tube feeding needs an important amount of care. A medical contraindication, a prudent medical

judgement that ANH would not change the outcome or even prolong the dying process or hasten death, or the decision that burdens outweighs the benefits would all be good reasons not to use ANH (Sheehan, 2001, 23-26). The restoration of health and the alleviation of pain are benefits of medical interventions. Economic, social and psychic goods are other important benefits concerned. It is important to consider benefits before the burdens, since no burden of interventions are allowed without any benefit for the patient, the community and the society (Ashley, 2006, 186, 189). Tube feeding is used when the patient has or risks malnutrition or hypercatabolism, which is an excessive metabolic breakdown of a specific substance or of body tissue in general, leading to weight loss and wasting. The artificiality of the act may seem to degrade what it is to be human, but one could argue that artificial help to survive is a human way of rendering life better. The artificial administration of natural products does not seem to have any bioethical implications, concerning the natural act of the feeding of a human being; it only shows that human skill and artistry were needed to produce it (Colombetti, 2009, 1083-1085). The question is if the technical invention replaces the human personal sharing of the meal and that something personal, spiritual and communal is lost that is essential in enjoying a good meal.

The alternative to ANH would be feeding by hand, an available but not always practical alternative. This is a possible option as long as the chewing and swallowing functions have not been obstructed by not using them or other complications that may occur. This may avoid the unwanted consequence of patients who after a while with ANH are no longer able to swallow properly. Feeding by hand does not expose patients more to aspiration than ANH does and establishes a contact between the dying person and the care-givers, providing the tenderness of human contact (CJBP, 2009). It requires more labour and a greater presence from people surrounding the patient. However, the time needed corresponds to a slow meal, and the quantities are reduced, thanks to very rich ingredients, which in concentrated form to satisfy a person's daily requirements.

## 6. How to investigate in theological ethics:

### is ANH proportionate to what it achieves?

This chapter will introduce the reader to what a proportionate method is within Catholic theological ethics and how it is applied to the question of this thesis. To convey this knowledge, the method will be inserted in its historical, philosophical and theological contexts, then the method will be described, compared and contrasted with other perspectives in theological ethics. Objective frames and subjective perceptions of benefits and burdens are discussed in particular, before outlining in a synthesized way in what the method consists and how it will be applied in this thesis.

#### 6.1 A real ethics

With the Protestant Moral Theologian James Gustafsson in his book *Protestant and Roman Catholic Ethics*, the view is here shared that every Christian ethical tradition contains gaps which can be overcome with new common solutions, and that the differences in approaches are not so large that it is not possible to further develop an ethical reflection in a common direction (1978, 139). However, this methodology begins within the Catholic tradition, makes use of its language, and deals with a rather Catholic debate, more known to its authors, while the conclusions are accessible to every person of good will and can be appropriated in a language closer to one's own tradition, whether philosophical, theological or scientific. This implies that a Christian ethic is coherent with the human experience; its tradition, its interpretation of the Bible, the philosophical methods, insights and principles chosen, the contemporary scientific knowledge and acknowledged methods. This presupposes that an adequate and difficult choice of preferred sources, contents and interpretations is made (cf. Gustafsson, 1978, 139-140). In this thesis there is an attempt to start with what is more known to the reader and lead the reader to what is lesser known and to some extent from the general to the specific and from the descriptive to the advisable.

Catholic ethic is traditionally rooted in reality. The reality, as we humans perceive it, is made of the relationships between people and their relationships with God and creation, although both these realities surpass human comprehension, God by definition and God's

creation because there is still more to be discovered in the universe. The reality is that what the limited and imperfect human discovers, or the reality is that what a human being has not discovered yet or does not have the ability to discover completely (regarding the mystery of God). The reality of God cannot be discovered in its entirety by a human being, while God is greater than a human being can realize, and it will probably remain that way also in heaven. By a person's choices, this person shapes the person's own self. In reality, there are friendships and relationships, meanings and purposes of life, which are founded in reality and which exist independently of the intentions and emotions of human beings. Humankind was meant to live in solidarity to better cope with its struggle to survive, but how often do humans instead not begin wars or destroying fratricides or reject their familial responsibilities to children or elderly people? This does not mean that intentions and emotions cannot be decisive for assessing an individual moral action. Since morality is based on reality, "what we ought to do is rooted in what we ought to be" (Overberg, 2006, 5). This implies that ethic is not only doing good, but also living good relationships (Bretzke, 2004, 10-12).

Such an ethic seems to be contradicted by many post-modern thinkers who do not accept that any structures that would be given by creation, whether they believe in a Creator or they ascribe creation to a mere chance of realized possibilities and lucky coincidences. However, Emerich Coreth S.J. (1919-2006), highlights that the fact that we ask questions shows that we are. If we were not real, we would not be able to ask any questions at all. The most fundamental premise of our questioning is being, is the reality itself (Coreth, 1964, 67-69; 115-118 and Coreth, 1973, 51). The post-modern thinkers, and among them are both some teleological pessimistic utilitarianisms and some deontological vitalists, claim that the reason of human beings is capable enough to judge the better moral choices preferable in any particular situation and would rather deconstruct the biases of these given structures in order not to be fooled by their appearances. It is true that the gift of reason is very precious to discover a real ethic; however, a person is a very restrained and frail unity. This person needs the exchange, experience and erudition of other people to find what is the most loving true ethic to follow. This makes a good communication between human beings necessary. Gary Aylesworth in his article *Postmodernism*,

summerizing some passages from the French post-modern thinker François Lyotard's *La Condition Postmoderne* written in 1979 or in English, *The Postmodern Condition: A Report on Knowledge*, 1984 writes:

Analysis of this knowledge calls for a pragmatics of communication insofar as the phrasing of messages, their transmission and reception, must follow rules in order to be accepted by those who judge them. However, as Lyotard points out, the position of judge or legislator is also a position within a language game, and this raises the question of legitimation. As he insists, "there is a strict interlinkage between the kind of language called science and the kind called ethics and politics" (Lyotard 1984 [1979], 8 in Aylesworth, 2015)

A post-modern ethic would justify the fact that one lets an institution take care of one's parents and that one neglects to visit them regularly if this seems to be the best choice. According to the Catholic tradition individuals have a responsibility to care for their family, and the conscience has the most important decisive role in the decision and how one ought to do this. Personal encounters, Christ's revelation in traditions and scriptures, and the nature of creation are also real sources to help the human person in one's decision and on which an ethic can be founded. Thomas Aquinas summarizes philosophical traditions of thought and refers to Boethius' *De hebdomadibus* when he says that goodness always tends to spread, that *bonum est diffusivum sui* (ST I, q. 27, a. 5 ad 2). God created the world with the aim of sharing his life and his love through his grace. God invites human beings to respond to his invitation to become intimate and loving friends and gives them the fortitude to be able to respond adequately to this invitation (Overberg, 2006, 19). According to John Duns Scotus, Jesus is the culmination of God's self-giving gift to the world (Overberg, 2006, 13). Jesus explains why God created the world and is the model how people should live in the world; thus, both who humans ought to be and what they ought to do.

“Again, if the fall were the reason for Christ’s predestination, it would follow that the greatest work of God [*summum opus Dei*—namely, the Incarnation] was essentially occasioned: greatest work, because the glory of all creation is not as great in intensity as is the glory of Christ. Hence, it seems very absurd to claim that God would have left so great a work [i.e. the Incarnation] undone on account of a good deed performed by Adam, such as Adam’s not sinning. Therefore, I declare the following: *First*, God loves Himself. *Secondly*, He loves Himself for others, and this is an ordered love. *Thirdly*, He wishes to be loved by Him who can love Him with the greatest love—speaking of the love of someone who is extrinsic to Himself. And *fourthly*, He foresees the union of that nature that must love Him with the greatest love even if no one had fallen” (John Duns Scotus, *Opus Parisiense*, Lib III, d.7, q.4 (ed. Balić) 13-15 in Dean, 2012-2015).

Thus, Jesus is the model of what a human being ought to be and do; however, what is it more precisely to be a human being? Considering human reality, Karl Rahner gives six traits that he finds to be characteristic of the human being (Rahner, 2003, 184-206 & Rahner, 1978, 26-32): that a human person is embodied and thus a historical being dependent on time, place and culture, although one does not by one's being determine the morality of a particular situation; that a human being is spiritual and therefore a thinking subject equipped with a will; that humans are social beings living in solidarity relationships with other people; that people are unique and therefore individuals with different genes, upbringing and influences; that people are free to choose whether they wish to be authentic people, and realize the idea of being truly human; and that a human being has the capacity to have a relationship with God. This last capacity is not part of being human, but a gift of God that can be accepted. To break one’s relationship with God would be what Catholic ethics calls a sin (Overberg, 2006, 15-18, 21).

## 6.2 A real decision

Teleological pessimistic utilitarianism does not accept that reality shapes ethics, that there are common elements of a human being that settle some questions of what a human

person ought to do, or that wisdom and past experience expressed in moral laws can have a decisive importance on the evaluation of a particular moral case.

Deontological vitalism does not accept that human reality can change with different times and cultures, that a human being has the right and the responsibility to follow foremost this human being's conscience, or that ethical laws or judgements might be too narrow to cover the reality of various moral cases.

Catholic ethic contends that "the understanding of reality [of the act] and of particular circumstances, including intentions and consequences, can yield a moral decision" (Overberg, 2006, 25). The understanding of reality includes insights into whether there are some aspects of an act detrimental or destructive to whom the human person ought to be and this is called a pre-moral evil. Theological, philosophical and scientific disciplines with human experience make it possible to decide whether something is a pre-moral evil. Then, one should try to embrace and consider the totality of an ethical situation with its circumstances, intentions and consequences to clarify with methods and principles whether this very act is also an act of what is called a moral evil that is a break in one's relationship with God. People generally do not have the possibility to know this in a clear and decisive way and have to rely on their conscience and faith to inform their reason as to what is the best in a given situation, recognizing that they could be wrong. A proportionate reason to do anything ethically good supports a value inherent in the goal of an action sufficiently strong to outweigh the pre-moral evil that is caused by the very same action. For a limited human being, it might be very hard to embrace the totality of any ethical situation.

Richard McCormick in *Ambiguity in Moral Choice*, when describing six criteria for discerning whether there are sufficient reasons (this is roughly equivalent to proportionate reasons) to do something. These are: to consider the social implications or consequences of an act; to ponder whether an act would be suitable for all people; to understand whether some cultural influences might bias the judgement if a reason is sufficient; to integrate the wisdom of past human experience in the judgement; and to let the possibilities inherent with religious beliefs enlighten the judgement of a moral dilemma. Thus, the sources of prayer, experts, people sensitive to human experience, traditions, authorities, colleagues,

friends, and even social networks ought to be consulted in a discernment process (McCormick, 1977, 95-96). This means that the "careful discernment of the values to be achieved as outweighing (not in our desire, but in reality) the disvalues involved" in an action helps an acting person to see whether there are sufficient reasons to cause possible pre-moral evil or not (Overberg, 2006, 28). If a human being always should respect life, there might be circumstances when it is permitted to kill someone; e.g., in self-defense, albeit one ought never to murder anyone.

### 6.3 Conscience

Human conscience is a personal self that tries to respond to situations which a person experiences. Conscience is a human capacity to know what is good or what is the better choice in a particular situation. With a general sense of values and a basic sense of responsibility, a person decides in the concrete situation what one ought to do. Human conscience implies a basic openness to the surrounding reality and a sensitivity to respond to unexpected new situations. Conscience is formed in time by experiences and insights to develop one's authentic values. This maturation to a personally understood and heartfelt knowledge can be accelerated by a regular examination of conscience. Conscience follows certain values and can be assisted by some authorities. Through conscience people choose what person they are and the basic values that they realize and express. The Catholic tradition has insisted that humans ought to be seriously committed to following their conscience. A person's integrity depends on whether a person follows one's conscience or not. (Gula, 1989, 127, 132).

In the depths of his conscience, man detects a law which he does not impose upon himself, but which holds him to obedience. Always summoning him to love good and avoid evil, the voice of conscience when necessary speaks to his heart: do this, shun that. For man has in his heart a law written by God; to obey it is the very dignity of man; according to it he will be judged. Conscience is the most secret core and sanctuary of a man. There he is alone with God, Whose voice echoes in his depths. In a wonderful manner conscience reveals that law which is fulfilled by love



of God and neighbor. In fidelity to conscience, Christians are joined with the rest of men in the search for truth, and for the genuine solution to the numerous problems which arise in the life of individuals from social relationships. Hence the more right conscience holds sway, the more persons and groups turn aside from blind choice and strive to be guided by the objective norms of morality. Conscience frequently errs from invincible ignorance without losing its dignity. The same cannot be said for a man who cares but little for truth and goodness, or for a conscience which by degrees grows practically sightless as a result of habitual sin (Vatican II, 1965, § 16).

Thus, people need to have some direction what they ought to do, while the conscience can be lost on the way to a good ethical decision through ignorance, although this would not be considered as a culpable fault. It would be another situation if the person concerned would not even bother to seek the true and good ethical decision to take (Overberg, 2006, 37).

There are three dimensions of the conscience; that is, the general sense of value or that one ought to do good; the search to discover the right course of action, recognizing and weighing values and meanings; and the actual concrete and evaluative judgement of an immediate action (Overberg, 2006, 38): similarly there are three stages in logically forming an opinion of a concept; that is, apprehension, discursive reasoning, and conceptual judgement whether something is true or not.

The dilemma with cases relating to the ANH for MCS patients is that these patients have no ability to listen to their conscience, or cannot express clearly what their conscience is telling them. Such listening applies only to those who can decide; that is necessarily someone other than the patient unless the patient has expressed the choice earlier. As each conscience is personal, it will never be a guarantee of whether the outsiders conscientiously will choose an option corresponding to what the patient would have chosen or not. The greater the knowledge that outsiders have about the patient and about the course of the disease, the greater is the chance that the assessments will be appropriate. The final decision will thus only regard exterior information, and it will be more difficult

for anyone's conscience to judge what is to be done. Therefore, one might expect the time for deciding what to do to be much longer than usual and normal.

#### 6.4 The principle of proportionality

The general medical condition and one's ability to pursue the spiritual goods of life are important aspects to consider when evaluating if one ought to prolong life through medical means. It is up to the patient or, in certain circumstances where the patient has lost his or her ability to decide for himself or herself, up to a designated proxy to determine what is in the overall best interests of the patient. A reasonable hope of benefit in terms of helping one to pursue the spiritual goods of life without imposing an excessive burden implies a moral obligation to prolong life with medical means. Thus, one is not morally obliged to prolong life with medical means when death is imminent and medical treatment will only prolong the dying process; when there is no reasonable hope of benefit (physiological, psychological, social, and spiritual dimensions) to pursue the spiritual goods of life; or when medical treatment imposes an excessive burden (physiological, psychological, social, and spiritual dimensions) and profoundly frustrates the pursuit of the spiritual goods of life. That is not morally equivalent to suicide; it is a courageous choice to recognize that there are higher, more important goods than the good of human life (Panicola, 2001a, 17). Thomas A. Shannon and James J. Walter call this tradition a method of teleological balancing of the impact of the intervention; however, it might be better described as setting a preference that the benefits are in proportion to burdens or harms that the patient, the family and the global society have to put up with.

#### 6.5 Longing and striving - a theological point of view

Henri de Lubac has pointed out the importance of the desire of God in the human being. Before the human being is aware of the personal existence of God, this desire may appear to him or her as a desire of life, love or light. To prolong life, human beings strive for a better health. Aquinas writes that everyone has it written in their human nature to love their own life and whatever is directed thereto (ST IIa IIae q. 126 a. 1). Even when striving for the goods of life and prolonging life with the help of medicine and a better

health, human beings are aware of the fact that they are facing death. It is inevitably a part of life that we have to die. If one sees death as one's worst enemy one will try to deny death and remove it from one's life, a rather common phenomenon in the Western contemporary civilization.

One can point out the importance in contemporary theology of viewing the human person as a whole embodied spirit, like Rahner, where what is merely biological will perish one day and where the historic identity, the personal, intellectual and loving aspects of the body will be glorified. This is in contrast to the more Cartesian view that would equate a human person to an imperishable spirit in a transient body, where the spirit may be not affected by the different states of the body.

#### 6.6 Different actual positions in Catholic moral theology

Proportionalism is not a single and developed moral theory, but one of a range of related approaches. Proportionalism seeks to give greater attention to the intentions of the agent and his circumstances, while rejecting what was seen as the legalism and rigor of the preceding tradition. The moral evaluation one undertakes is dependent on the acting person's intentions, the circumstances, and the act itself. An act viewed from the exterior can seem to be bad that is to be an act of pre-moral evil. Every form of proportionalist thought argues that if the act has some bad consequences, then there must be sufficient reason to cause these bad consequences.

Revisionism argues that the relational meaning and significance of an act is a *progressive reality* (Salzman and Lawler, 2008, 81). Thus, we do not really know the *actual intention* from choices of contraceptive acts. This has at least two meanings: the first one would be that this intention cannot be known from the perspective of the outside observer, and that is rather traditional: "to be able to grasp the object of the act which specifies the act morally, it is necessary to place oneself *in the perspective of the acting person*" (John Paul II, 1993, §78). The second less probable meaning would be that it is not even possible to determine the intention of the involved persons; that is that they do not entirely know it on their own.

Among the scholars who rejected the traditional or the scholastic natural law theory in the conciliar era were Germain Grisez, John Finnis and Joseph Boyle who articulated what has been called the *New Natural Law Theory* or the *Theory of Basic Human Goods*, with a deontological perspective. They articulate a still evolving list of these basic human goods including human life, knowledge, self-integration, practical reasonableness, justice and friendship, religion and holiness, marriage and parenthood. These goods are said to be self-evident, not in the sense that they are known to all, but in the sense that once the terms used to express them are understood, a person will recognize them as human goods. The human goods are the ground on which these moral theologians build up their normative existential principles constituting a moral theology. All that is created are goods and remain goods as long as they are not lacking in goodness by some distorting, damaging or corrupting factor. Goodness is thus fullness of being. The good of an organism's health is to live more fully. One may for example choose an intelligible good to override emotional repugnance to a sensible evil. There are goods that are better than others and the moral choice is an important act of moral theology. By considering that good things fulfill human persons one begins to understand that there are good persons. Basic human goods are aspects of a human full-being. Bodily life is a basic human good. Good persons making free choices are fulfilled by existential choices. Self-integration leads to inner harmony, reasonableness and authenticity to practical insights, and justice and friendship lead to peace, and friendship with God leads to an increased friendship. There are other substantive or non-reflexive goods where there is no choice: Life and health fulfill bodily beings; knowledge and truth fulfill intellectual beings; and, leisure and skills fulfill cultural persons. These substantive goods are vehicles for existential goods. However, goods cannot be compared with each other (Grisez, 1983, 116-137, 147). Persons constitute themselves, individually and in communion participating in goods. People are good when they are morally good. A morally good life lived in harmony is an essential part of human fulfillment. This concept of goods is problematic because it does not recognize that goods must often be weighed one against the other (Panicola, 2001b, 29). A moral theology tries to analyze this fulfillment as something good in relation to God. "Moral theology reflects upon the truths of faith" and "how faith should shape Christian

life" (Grisez, 1983, 6). It seems that this type of moral theology is rooted in only a part of reality, that is in its intelligibility. Grisez uses a dialectical method seeking a better understanding of the truth in which one is already living. "One considers truth of faith by comparison (*analogia*) with truths of reason, with one another, and with the ultimate fulfillment to which God calls us in the Lord Jesus" (Grisez, 1983, 31) and judge which moral answer is in harmony with faith.

"A virtue is a disposition to act, desire, feel that involves the exercise of judgement and leads to a recognizable man excellence, an instance of human flourishing" (Yearly, 1990, 2 in Spohn, 2007, 28), depending on the cultural setting. One uses virtues to set personal and social goals that one encourages oneself to seek (Harrington and Keenan, 2010, 4). Virtue ethics finds that the goodness of an action is connected with the goodness of the person acting and this person's situation and relations. A good act is an act that a good person would have done in the current situation (Åkerlund, 2016). Virtue ethics focus on the question: Who ought one to become? According to virtue ethics there are some "characteristic ways of behaving that make both persons and actions good" (Harrington and Keenan, 2002, 23). Some moral theologians are oriented to a life of human and divine love requiring a transformation in virtue over time, where the good life is measured by how virtuous it is (and thus how fulfilled it is). The moral evaluation is interested in the agent's character. "A good character produces practical moral judgements that are based on beliefs, experience, and sensitivity" (Spohn, 2007, 28) rather than on moral principles. Actions are important as a sign and a motivation for some values and commitments. The ordinary life is of a greater interest to virtue ethics than specific moral questions (Harrington and Keenan, 2010, 6). The difficulty is only to grasp all virtues in a glimpse or to choose the virtues that are to be considered in a certain moral case, and which is the end or ends that ought to be considered in priority. However, charity (in ancient times more often humility or prudence) is often put as a moderating virtue giving the intuition how one ought to decide in the very moment when the decision is necessary.

## 6.7 Proportionate to what?

Thomas A. Shannon and James J. Walter recognize some noteworthy shifts within the Catholic tradition, concerning the teachings of the magisterium: the method of reasoning has shifted from a proportionate reasoning in 1980 to a reasoning being influenced by deontological considerations in 2005 (Shannon & Walter, 2005, 653). This is especially true for the areas of medical and sexual ethics; for example, when it comes to giving ANH to VS patients. These areas are governed by mandatory principles with no exceptions and unqualified by the circumstances, like in social and economic ethics, where there is no corresponding return to obliging commandments. Here experiences, different historic and contemporary perspectives, circumstances, and contexts contribute to provisional conclusions, reshaped by newer data. Shannon and Walter remain persuaded that there is also a shift to deontological reasoning in the area of death and dying, complemented by categorizing interventions as ordinary or extraordinary.

The Catholic tradition, on the other hand, has used a proportion-disproportion test as the way to resolve issues surrounding the dying (Shannon & Walter, 2006, 173). End-of-life issues are analyzed following the tradition by this patient-centered methodology, trying to see whether there is a sensed proportion between the medical means and the benefits of these measures to the integral situation of the patient. This could imply that the medical means considered might be called ordinary and be required to be given to the patient. An example of this type of proportionate reasoning subscribing to this method is the *Document on Euthanasia* from 1980. The Pontifical Commission *Cor Unum* commented on this document thus:

The fundamental point is that the decision should be made according to rational arguments that have taken well into account the many and various aspects of the situation, including what effect will be had upon the family. The principle to follow is, therefore, that no moral obligation to have recourse to extraordinary measures exists; and that, incidentally, a doctor must follow the wishes of a sick person who refuses the measures (Cor Unum, 1981, 4).

The withdrawal of ANH is sometimes compared to killing someone by omission, and the condition of the patient seems to have less importance in this reasoning (Shannon & Walter, 2005, 655). However, there is a considerable difference between judging a medical treatment inefficient and not helpful to a patient, even unconsciously, when the patient needs help.

There is further a difference between looking at some physical effects and the moral evaluation of a person's integral situation. The well-being of the whole person is what is important, when one considers whether to use a therapeutic intervention or technology. "Therapeutic procedures that are likely to cause harm or undesirable side-effects can be justified only by a proportionate benefit to the patient" (USBBC, 52011, 21). "The real purpose of the omission was to relieve the patient of a particular procedure that is of limited usefulness to the patient or unreasonably burdensome for the patient and the patient's family or caregivers" (O'Rourke and Norris, 2001, 205).

Catholic moral theology has changed its vocabulary to proportionate and disproportionate means from the distinction between ordinary and extraordinary means, to avoid the tendency to interpret the terms ordinary and extraordinary in an abstract or too generic manner. Making moral decisions ought always remember the specific conditions of the patient in question and not only fundamental theories. Using the terms in an abstract and generic sense would equal seeing only the economic, medical and physiological aspects of a procedure problem without considering the general condition of the patient and his or her situation in life. The church insists that the ordinary and extraordinary aspects of a procedure can only be taken into account after that the general glimpse of a patient's life has been overviewed (Ashley, 2006, 185-186).

As has been noted, in a series of statements from the magisterium, like papal congregations and ecclesiastical commissions, there is not only a presumption in favor of ANH, but a moral obligation to use ANH for VS patients. This seems to interpret Catholic tradition in a rather one-sided way, forgetting other Church teachings that says the condition of the patient must always be considered. It is never simply technology.

Catholic moral theologians mostly find that life is not to be devaluated in any circumstance or in such a medical difficulty as the permanent coma. The question is

whether one has a moral obligation to maintain this valued life, while the biological life does not equal all the life of a human person, since it is created and limited. There are three main options to answer this question. The first opinion views ANH as ordinary care and morally obligatory. The second viewpoint contends that ANH is a medical treatment that ought to be offered unless it is physiologically futile or excessively burdensome, that is, when there is no reasonable hope of sustaining life or when ANH pose excessive risks or burdens. The third opinion states that ANH may be discontinued for the patient in VS primarily because it offers no benefit to the patient and secondarily because it may occasionally impose a grave burden (O'Rourke and Norris, 2001, 201, 206).

[W]hen a proposed intervention cannot offer the patient any reasonable hope of pursuing life's purposes at all or can offer the patient a condition where the pursuit of life's purposes will be filled with profound frustration or with utter neglect of these purposes because of the energy needed merely to sustain physical life, then any medical intervention (1) can only offer burden to the life treated; (2) is contrary to the best interests of the patient; (3) can cause iatrogenic harm or risk of such harm; and (4) has reached its limit based on medicine's own principal reason for existence, and thus treatment should not be given except to palliate or to comfort (Shannon & Walter, 2005, 662).

#### 6.7.1 Proportionate and disproportionate or ordinary and extra-ordinary

There is a diversity in the comprehension of what is an ordinary treatment: is it a classification of a certain technology, which when it is ordinary becomes morally obligatory; or is it what is usually done in hospitals, a routine or customary medical treatment; or is it an evaluative process of a treatment that proportionally is seen, or predicted, giving more benefits than burdens (Shannon & Walter, 1988, 643-644). This is only one reason to abandon the ordinary distinction and instead use what is proportionately reasonable to do in a specific case.

To say that ANH is always a moral obligation to VS patients is a problematic statement. There are limits to medical care that a doctor in accordance with general



practice may end. It seems not to be a convincing logic behind prohibiting the withdrawal of ANH without considering whether it ought to be seen as a medical intervention or not: a vegetative state is a condition that must be treated, and like every treatment, that treatment can be ended by a competent physician and this termination of treatment morally justified. The problem is then to understand why ANH always must be given, when a treatment can be ended. One can say ANH is not a treatment, it is a basic care, and every person has the right to receive basic care as long as the person is alive. Here, it will be contended however, that ANH is a medical care when it comes to patients in a vegetative state, and therefore it can be ended when it is, and only when it is a treatment.

The terms like basic care, aggressive treatment, and therapeutic measures concentrate more on the treatment, than on the whole person treated. What is medically routine and therefore medically ordinary is confused with what are the proportionate reasons to judge an amelioration plausible, making the intervention morally mandatory (Shannon, 2008, 915).

Some people would say that care is disproportionate for a patient who will not have any cognitive or affective life until death. The intervention of ANH cannot give the patient his human life back, improve the health situation, but only prolong the physical or biological life that is not capable of surviving by itself and with little hope of reawakening.

#### 6.7.2 Burdens and benefits

Would it not be a methodological error to state abstractly that there are no cases where the ANH are neither useless nor excessively burdensome, like May does in his article *Caring for persons in the persistent vegetative state and Pope John Paul II's March 20, 2004 address on life-sustaining treatments and the vegetative state* (2005, 544)? He states that in ordinary circumstances in our society today it is immoral to withhold or withdraw nutrition and hydration provided by artificial means to permanently unconscious and however not terminal patients. Cataldo states in a response to Garcia that he is of the opinion that the relevance of giving ANH "depends upon the individual circumstances. The fact that bodily life is an ultimate end in its own order does not preclude the possibility that in any given case nutrition and hydration will not be a proportionate

means of conserving life” (Cataldo, 2008, 155). When considering whether ANH is proportionate to a patient in vegetative state, there are some measures that ought to be considered: firstly, it might not be proportionate; secondly, there are no or very small benefits, and thirdly, the benefits are “too painful, too damaging to the person’s bodily life and functioning, too restrictive of the patient’s liberty and preferred activities, too suppressive of the person’s mental life, too expensive” (May, 2005, 544).

A treatment must offer some hope of health. A medical treatment can be useful to the medical goal of nutrition without helping the patient to recover from one’s pathology. Therefore, it is important to evaluate the use of a treatment in the context of the patient’s health. A useful treatment ought not to be burdensome especially so in the view of the conscious patient, or as expressed in an advance directive earlier by this patient, or by the patient’s proxies of a currently unconscious patient. The patient may not like to live the life that a certain treatment can give, and therefore refuse the treatment.

For a patient, it might be an increased burden to live with help of technology if this person is living merely at the biological level with no hope of an ameliorated health or possible temporal or eternal achievements. For the VS patient medicine cannot improve the person’s health and wholeness. The burden is thus not to be assessed only from the perspective of effectiveness of the technology to achieve its limited goals; it is to center on the VS patient and this person’s possibilities to live a human personal life. The VS patient might not be able to experience this burden. However, it might be just as real for the family or the caring staff.

In sum, the burdens of a treatment must not be so burdensome that they are not proportionate in a good and reasonable proportion to the benefits the patient expects to receive from the same treatment.

### 6.7.3 Objective frame of reference and subjective perceptions or preferences

There are many criteria whereby one establishes to what extent the means to be used and the end being sought are proportionate. There are objective criteria, like those of the nature of the measures proposed, how expensive these measures are, whether it is just to use them, and what options of justice there are in using them.

Other criteria are subjective: whether to reanimate certain patients, risking to cause them anxiety or uneasiness. An option would be not to reanimate them in order not to burden them too excessively. Many are those who would find it excessive to reanimate someone to a vegetative state in the last phase of an incurable disease; however, not all people have the same opinion (Cor Unum, 1981, 4 & Shannon, 2008, 903-904). On the other hand, has one then given the patient enough of the autonomy necessary to make the choice whether that person prefers to continue the treatment or not?

The question is whether ANH is an objective criterion and if foregoing and withdrawing ANH would be to put an end to a patient's life. It seems fair to say that the question contains both objective and subjective elements. Generally, there is the proper finality of ANH, and it will be possible to establish whether the finality is respected and fulfilled in the particular case. If it is respected, there are still some questions to clarify whether the nutrition and hydration are objectively available or not, that is, whether it is physically possible to give ANH; if there are measures to establish whether the patient is able to receive or assimilate the ANH or not; or whether there are other medical complications or diseases hindering the care-giver to practically provide the ANH (cf. Shannon, 2008, 908). However, it is a subjective criterion how this patient will find it good, pleasant and tasty to receive ANH or not. For a VS patient, we can today only assume that there is no response to this subjective criterion: we do not know at all whether the patient likes the ANH or not.

One could reflect on the methods one can use to arrive to clearer knowledge on when an intervention contributes to a good life and when such an intervention is futile and would better be foregone or withdrawn. Perhaps a trial experiment for some centuries will show us the likelihood that a certain state of consciousness patients reemerges so that they can live a flourishing life could give some insights. Maybe the dormitories of VS patients in hospitals all around the world will provide the knowledge necessary to come to a decision. Or might a long-time VS patient be too burdensome, economically to the world economy, and socially as long as there unjustly are not enough beds for every VS patient in the world for us to find out the truth.

One can characterize a treatment as excessively burdensome when it produces so much pain and suffering for the patient that the patient feels it is too much. Thus, it is up to the patient to decide what level of pain one can bear and how much medication is good to him or her. This is a rather subjective criterion where the patient is the main concern. Vegetative patients cannot communicate these impressions, and it is quite difficult to judge for them. Thus, this is not a useful criterion for them. On the same grounds, it is difficult for them to express that a treatment is repugnant in their opinion. Where the proxies or the staff of caregivers finds a treatment too repugnant; this opinion has to be valued considering the general benefit of the same treatment for the patient himself.

A criterion where it is easier to establish the boundaries and use of it is if the treatment impairs bodily functioning. A very discussed subject concerning persons in a vegetative state is if ANH impairs the function to swallow; and if it does is this a reason to devalue the treatment. However, other aspects ought to be discussed too. What are the results of an ANH treatment on the body of vegetative patients, do they deteriorate from anything other than only getting older? Which necessities does the treatment require from the caregivers: do they need particular skills? If the patient is imminently dying or when nutrition and hydration are not accepted by the patient's body, the case seems rather objective to settle; to establish whether a treatment is burdensome to someone else, either the patient or the surrounding people, is much harder to decide.

## 6.8 Human flourishing

Considering the spiritual end, one might think that human flourishing would be better served without ANH. Others would say that although this life is not a human flourishing life, it is a life maintained by the care given and enhanced if receiving the human personal relationship by visitors and health care personnel. ANH can indeed be a proportionate good for the VS patient since to receive the goods of human relations, physical training and an amiable environment is to take part in what a human flourishing life is. It would be wrong to distinguish too far between a physical life and a mental life. The outcome of the intervention can be hard to predict, and when there is a serious doubt whether the person may wake up and participate in human activities, it is better to

continue this service of keeping the body's muscular parts, nervous system, and skeleton intact and enhance the quality of life by sensitive and communicative stimulation.

The question is whether persons in a vegetative state can pursue the spiritual goal, and in what this goal consists. Is it possible to be an unconscious patient resting passively on a couch in a hospital and fulfill the highest ends of charity? There is a choice to make whether to let someone die or to let him continue living on earth. The benefits of exercising the virtue of acknowledged dependance might be greater for the care-giver than for the receiver of the care, especially an unconscious patient. However, the receiver does benefit from this care, the question is whether it is a proportionate benefit to the efforts given. Especially, when there are economic and psychological burdens for families who have been caring for a patient more than a year, these can become too burdensome. The society is often considered to have a duty to support these families with volunteers, or by centers for this type of health care (Degnan, 2008, 53).

#### 6.9 The method used: what seems the most pertinent way of treating this issue

The thesis uses an approach to ethics that is starting with the human person and the human being's basic needs of love to God and one's neighbors that have to be ordered and satisfied properly if the person is to flourish and become a good person. Therefore, an inductive proportionate method will be used for this ethical analysis where objective holistic ends and deontological considerations are complemented with a reflection of some subjective virtues to achieve these ends along with the virtue of *epikeia* looking at the meaning of laws, rules and principles, and not only to their literal meaning or biotechnical achievement. Holistic in this context means an ethic that strives not to reduce the human person to one or a few of its parts, either physical or intellectual, and thus avoid a mechanistic biotechnical view on the human person as only bodily. This holistic approach thwarts a disrespect for the human life in its weakest forms and integrates Catholic social teaching principles and virtues including solidarity and subsidiarity (Panicola, 2007, 52-54).

Laws deal with human actions concerning particular situations with particular circumstances. Thus, it is impossible to make universal laws that can take into consideration all the possibilities for moral action in every single conceivable moral action; instead laws are made for what usually happens. However, there will be times where even a really good law, if applied to a certain action, will not contribute to the common good, which is the main purpose of the laws. Therefore, it is probably better not to follow the law in these precise circumstances.

That the ethical method is labeled proportionate means that it:

is thus context sensitive; given one set of commitments and responsibilities, the benefits of prolonging life might be proportionate to the harms, but given a different set, these benefits might not be. To say, then, that a treatment offers benefits that, for this agent, are proportionate to threatened harms (Tollefsen, 2008, 218).

This is to say that it is morally advisable to act in a certain way, where the treatment has benefits that are proportionate to its burdens for the patient in question. It follows that it would be unreasonable for the agent to refuse a proportionate treatment. However, it would not be immoral not to follow such advice: there might be harmful side effects like infections, threatening burdens, and it is comprehensible to want to avoid these burdens like spending money or accepting the pain of a slowly deteriorating health.

Here, the proportionate method of reasoning will be used because it examines the impact of the intervention on the patient. It seems to better describe and give better solutions to a series of serious problems within Catholic moral theology. The judgement of what is morally good cannot be detached from the clinical situation of the patient in VS receiving or maybe going to receive ANH. There is a subsidiarity to be respected: it is the patient who is the proper moral person that has to be honored, when the decision whether the intervention is proportionate or disproportionate in accordance with traditional guidelines and basic moral principles (cf. Shannon, 2008, 902). Thus, every generalization ought to be made out from concrete results. The proportionality is evaluated in a particular situation and never in a mere universal guideline. However, the proportionality

is evaluated not only to the immediate effects on patient welfare, but more generally to the overall condition and prospects of life. This corresponds more closely to Catholic moral theology (Colombetti, 2009, 1091; Cahill, 1991, 110).

There are problems today in health care that the proportionate way of reasoning may help a human person to solve: the focus on therapy rather than care, concentrating on the objective physiological benefits of nutrition and hydration, rather than the whole person or neglecting the context of the whole patient. "While ANH certainly fulfills its purpose of providing nutrition and hydration, the larger moral issue is what impact does ANH have on the overall welfare of the patient? The focus needs to be the patient, not a particular biological system or organ" (Shannon, 2008, 911).

The general condition and prospects of the patient constitute the criterion of care. Determining benefit in health care demands an important subjective component: what is beneficial for one person may not be beneficial for another, and what is beneficial at one point might not be beneficial in another point of a person's life, what is beneficial to the individual might be more beneficial to this person than to the community, and what is beneficial in terms of intervention might not be beneficial in terms of receptiveness and presence that is to be able to receive the intervention well, and to manage to be present to other people, after the intervention (Have & Jos, 2014, 123; Wildes, 1996, 510).

The benefits of treatment include preservation of life, maintenance or improvement of health, and relief of discomfort. The burdens of treatment to be properly taken into account may include pain, discomfort, loss of lucidity, breathlessness, extreme agitation, alienation, repugnance and cost to the patient. Sometimes, the burdens of treatment may also include excessive demands on family, caregivers, careers, or healthcare resources, and the futility of a treatment.

There might not be a single solution to this problem; however, there are nuances worth exploring and making it easier to come to a moral judgement in a particular situation, influenced by national laws, cultural specificities, and individual preferences. This discussion is made possible thanks to contemporary technical means to maintain life. There is a form of technological imperative, obliging the contemporary human person to realize every medical capacity that is available (Shannon, 2008, 895). Does the treatment

restore life and health, or does it prolong, or even intensify, the patient's dying? The fact that life is not an absolute value needs a more critical examination (Shannon, 2008, 916).

It might be important to state that this thesis tries to make an evaluation in theological ethics out of a particular case along the guidelines of a relational and responsible proportionalism that is not one of sheer calculation, where one good is compared with and balanced against other goods, but where the means available are objectively proportionate to the prospects for improvement (John Paul II, 1995, § 65, 68). It is a consideration whether one has to change some conditions of life to render it a more realized form of life.

When now the master thesis' method has been outlined; it can be used on this thesis' problems. First, one has to make an important distinction between the withdrawal of ANH, which is being investigated by the thesis, and euthanasia, which is not here subject to investigation, but with which the withdrawal of ANH is easily confused.



## **7. What would it mean if withdrawing ANH were equal to euthanasia?**

The morality of withdrawing or foregoing ANH will be discussed in this chapter in relation to questions like euthanasia, palliative sedation and terminal illness, with the aim to discover the possible differences and similarities and in what they consist. The problem with ANH is that one cannot draw a sharp distinction between life and the means used to sustain life (Wildes, 1996, 510). Indeed, withdrawal or removal of ANH from patients with disorders of consciousness (DOC) can be viewed in many ways: active euthanasia, passive euthanasia, a medical technology, basic routine care or more than routine care, morally obligatory or not, all depending on personal circumstances. This variation in views "suggests substantial ambiguity of the moral status of feeding technologies for PVS patients" (Shannon & Walter, 1988, 625-626).

For believing Christians, human life is considered a gift from the Creator and received with the responsibility of an authentic stewardship of life. The purpose of life is in the friendship with God and living with the Eternal forever. "Eternal life is therefore the life of God himself and at the same time the life of the children of God " (John Paul II, 1995, § 38). Judging a treatment and the risks of dying they will consider whether the treatment is able to enhance one's relationship with God. If this seems not to be the case and some certainty thereof is achieved, then a Christian will consider whether allowing the patient to die is a better alternative than to prolong the gift of life on earth. This is not an easily resolved question and an effort is made to take the overall state of the sick person into account including this person's physical and moral resources. Rejecting additional medical efforts which are not proportionate to the actual circumstances is neither to reject life in itself, nor God who made life possible: it is not euthanasia, it is to accept the limits of the human condition in the face of death and allowing somebody to die for legitimate reasons, either no hope of benefit or excessive burdens (Ashley, 2006, 182-183).

### **7.1 Arguments in favor of euthanasia**

A common argument for euthanasia, which today seems to have great impact, is the principle of respecting the patient's autonomy, combined with the principle of doing good. This would mean that doctors have an obligation to act in the interests of the patient and

give the patient a lethal dose of a drug if this does not harm anyone else. The difficulty with this argument when it comes to DOC patients is that most people have no or very little ability to express their autonomy, and that euthanasia evades the actual conditions of human autonomy.

Proponents of euthanasia argue that the doctor's role to alleviate suffering is as great as their duty to preserve life. Suffering is seen as something useless, an evil that justifies relief, even if it means hastening death (Fernandes, 2001, 391 and Pellegrino, 1997, 246). Some people prefer death to boredom. Doctors would then be obliged to provide the requesting patient euthanasia.

Another argument for euthanasia is the argument for a dignified death: A long drawn-out process in the hands of various machines with the patient more or less aware of what was happening and without control over one's own life may seem like a very undignified situation for a human being. There are conditions a person does not need to accept to live through. Biological life is not the whole or even the maximum value of a human being's life (Overberg, 1989, 23-26). What is the point of living without any meaningful content (Lo, 2010, 55)? Personal relationships, exchange of ideas, to live in community with other people's values in a person's life, all fill life with meaning. Euthanasia gives no dignity in death, but it may prevent the dying person from ending up in an undignified situation before one's death. This is so, under the condition that one does not consider euthanasia in itself to be unworthy of a human person (Lo, 2010, 60). Patients with DOC can be viewed as persons with no dignity.

A third argument for euthanasia is the argument that active euthanasia (with intent to kill) does not differ significantly from the passive euthanasia (with the good intention of letting someone die with a sufficient reason). Because passive euthanasia is permitted by law in many countries, why not allow active euthanasia. If one regards death as something good, an active killing can be preferred to a passive letting die, because it is a faster way to reach the intended goal. Cannot the burdens of living for oneself and for others in the community seem entail worse consequences than with intentionally causing another person's death? Euthanasia may be considered to preserve the dignity of the patient's life, so that the life does not end in pain and anguish (Boonin, 2000, 161).

## 7.2 Arguments against euthanasia

A first argument against euthanasia is the principle of life, the inviolable dignity, sometimes called the principle of the sanctity of life. This can be justified philosophically when a person realizes that human life has value as the basis of every human action and as the foundation of every community. The value of the sanctity of life can also be justified theologically: a human being is subject to God's authority, and no person has the right to destroy what God has created.

It would be wrong if the society adopts a norm, Boonin argues, which runs contrary to one of that society's important values. It would only be possible to have a law allowing euthanasia, if euthanasia would be a good thing in itself, creating more happiness than suffering in absolute terms (2000, 165-166).

Euthanasia has consequences not only for the lives of the people who choose euthanasia out of free will, but for all human persons who are in a medically similar situation to those choosing euthanasia. The life situation for people in similar situations can be even more difficult and be felt even heavier than it otherwise would have been (Boonin, 2000, 165-166).

Another argument against euthanasia is that if one permits euthanasia, the confidence in the medical profession risks being weakened. The patients will not be as confident that they will remain alive after the doctor's visit. The purpose of the doctors' work is that they cure the sick and preserve human health and life. Euthanasia is not compatible with that purpose.

Another argument against euthanasia is the argument of the slippery slope in which the patient's voluntary request to have euthanasia turns to patients involuntarily being euthanized (Huxtable and Moller, 2007, 125). The slippery slope is an argument warning that if you take the first step, you will continue into a line of not necessary consequences, then at least probable consequences and move towards a position that is (far) worse than the starting position (Walton, 1992, 1). The fear of dying, of being a burden to one's family and friends and concerns with depression are factors that may lead to the choice of euthanasia (Boer, 2007, 540). The boundaries when one might use euthanasia are not clear and if one permits someone to be euthanized, there will always be

a subsequent question, if it ought not to be permitted to euthanize another person in similar circumstances too. The risks for a slippery slope are real and the criteria ambiguous considering the widened application of the euthanasia legislation in the Netherlands. Establishing criteria that are grounded in different levels of consciousness has a real basis and connection with reality. It is objective criteria grounded in human nature, as long as the pre-supposition that someone in a stable vegetative state more than a year will not recover is true.

In line with these general arguments, here will be given the counterarguments to the arguments proposed in the preceding section:

The risk with offering euthanasia is that one then unilaterally seeks simplistic solutions to diseases, instead of searching for alternative forms of treatment, palliative care and new curative drugs. Euthanasia prevents a prolonged suffering, but also prevents a deeper understanding and development of life and a possible reconciliation with one's own reality (Lo, 2010, 59). The search for what most benefits the patient, and what causes the least suffering continues. The treatment with ANH is often combined with other care.

The difficulty with the argument of a dignified death is to indicate the criteria of unworthiness that are sufficient for accepting euthanasia. Moral or psychological factors ought to be the basis for such an assessment. Are factors such as incontinence, dependence on others, dementia, coma, and sedation conditions which would be sufficient grounds to give patients euthanasia? There is a need for a broader holistic view of the human person who risks being relegated to a biological-psychological unity (Lo, 2010, 66).

Those who argue against the argument that active euthanasia does not differ significantly from the passive euthanasia emphasize instead the difference between a doctor who as a moral agent kills a person and a doctor that lets the patient die of the consequences of a disease, a disorder, or an injury. The question is what consequences the death causes for the doctor and for others in the community (Seay, 2005, 526-528). In some situations allowing a patient to die would be the same as killing; that is, when there is no proportionate reason to let the person die. However, if there is a proportionate reason, it is very different from killing (Collvin, 2014, 5-13).

### 7.3 Purpose and intent

The purpose of the act of suicide or euthanasia is to end the life of the patient. The purpose of the act of allowing death to occur is to avoid performing an action that is either futile or more burdensome than beneficial (O'Rourke, 2007, 51). The death is not caused; merely one's inability to impede it is accepted (Shannon, 2008, 902).

Stopping ANH is not under normal circumstances euthanasia and if it is euthanasia, "this needs to be demonstrated by showing convincingly that a particular withdrawal of ANH is done with the direct intention of causing the death of the patient rather than the patient's death being an unintended, though foreseen, consequence" (Shannon, 2008, 914).

Gómez-Lobo wants to test if withholding or withdrawing medically assisted nutrition and hydration always is euthanasia by omission. He writes that in order for this sentence to be true, the agent must always have this intention to be able to perform the act. This is true for active killing, and Gómez-Lobo wants to determine whether it is true for withholding or withdrawing ANH as well.

Gómez-Lobo goes on to state that omissions are of a different nature than active killing. Omissions do not cause death. What is left out has been hindering a prior illness or weakness to cause the death of the patient. So turning off a life-sustaining machine would not actively kill the patient. An omission can either have the intention or lack the intention of letting someone die. Sometimes one omits further treatment because it has been proven ineffective to continue the treatment. The patient will die; however, the main cause is the illness, to which is added the inefficiency of the treatment, where ANH is often only a part of the treatment. However, there is no intention to let someone die, rather, one has no knowledge or possibilities to cure the person. Then, there is no obligation to give a medical care or an advanced medical treatment. There are legitimate reasons to let someone die, when valuing life and yet accepting to forego life, or when caring for the sick without accepting an excessive medical treatment. Thus, an omission may be or may not be intending the death of the patient. An external judge may not be able to see the difference. Some trust in the judgement of the responsible physicians whether a treatment is futile or burdensome seems to be required or at least salutary. This applies to our case: there are

situations when an underlying pathological condition makes it impossible or really hard for a patient to eat and where a gastronomic tube-feeding is necessary.

Although the shortening of the patients' lives is one foreseeable result of an omission, the real purpose of the omission will be to relieve the patients of a particular procedure that was of limited usefulness to the patients or unreasonably burdensome for the patients and the patients' families or caregivers. However, would the burden for the care-givers alleviated by withdrawing ANH not be replaced by another heavier burden on their conscience if they would let the patient die? Only if this responsibility is integrated in a holistic view of the care-givers, including the spiritual goods of the person, only then the withdrawal can be permitted and contribute to the common superior good.

According to O'Rourke and Norris, removing ANH "does not mean that the direct moral cause of death is starvation or dehydration. Rather, the pathology which directly causes death is the dysfunction of the cerebral cortex". Due to the pathology the patient is unable to eat and drink on his own and would die of starvation and dehydration, and up until the removal of ANH, there have not been these effects.

Futile results in ameliorating the patient's health condition and poor future prospects or social, economic, and personal burdens to the patient or to the patient's proxies or to the community may lead the physician to forego ANH. The physician could then want the patient to die; however, it is more probable that he wants to alleviate the burdens of a futile treatment and has no intention to kill the patient. The patient is not by this automatically regarded as worthless, unproductive or lacking dignity. In the case of futility, there is a choice to cease a treatment or to let it continue.

The success of medically assisted nutrition and hydration can be measured partly by the goal of nourishing and hydrating the patient and partly by the improvements or deterioration of the patient's general pathological condition. When ANH is failing to nourish and hydrate the patient, it is clearly futile and unnecessarily burdensome. However, a good judgement must be made after a year without any improvements of health, if it is only natural aging or perhaps also the ANH which let the patient's general pathological condition deteriorate or, if possible, not change. Modern technology develops more and more efficient methods to reach the immediate goals, here of nourishing and

hydrating. The patient is kept alive longer despite a serious pathology. Will this be only a gain of earthly living time or also an increased suffering? These methods may then be less futile to achieve the immediate goals. However even so, quite futile, when integrating more parameters of a good health, that is, when considered in a more holistic perspective. Keeping alive an unconscious patient that is unable to swallow for twenty years might seem worthless, if you can be reasonably assured that no improvement will be made. In a moment in medical and moral history when modern technology permits us to consider most measures of health sustainment proportionate to the costs and efforts that human beings have to contribute for the intervention to succeed, we are brought to consider also the futility in a broader perspective for the patient's general condition (Gómez-Lobo, 2008, 107-109).

According to the Catholic moral tradition it is never permitted to have the proximate intention to procure death, either of those requesting the removal, neither of those effecting the withdrawal. An eventual withdrawal must never be an intent to kill, only an accepting of a situation, where the patient is no longer able to realize his or her dreams, projects, and goals of life.

The withdrawal of ANH is not euthanasia, since the death is not directly provoked; it can be viewed as a grave omission, while death is not induced by the pathology, but a result from malnutrition. The continued supervised living of the patient who is in a stable vegetative state after a sufficiently long period of observation offers, however, objective evidence that life support may be removed because there is no hope that the patient will ameliorate from the patient's disorder of unconsciousness.

It is inappropriate to call withdrawing ANH euthanasia. The patient dies from the effects of the pathology that hinders the patient's ability to eat and drink normally. With euthanasia one is deliberately trying to kill the patient. However, in withdrawing or forgoing ANH "the intent is either to end a procedure that no longer benefits the patient or to prevent the person from being entrapped in technology" (Shannon & Walter, 1988, 641). When a person has been declared to be in a VS, this patient will never eat; the person will always be fed. "The inability of the patient orally to eat or drink is morally relevant because this particular physical condition is one of the manifestations of the particular

illness (...) and is not to be examined in isolation from the totality of the patient's condition" (Shannon, 2008, 911). Absorbing food is not a voluntary act and the circumstances are not a friendly meal, but a medically assisted liquid protein diet, that one hardly would label as food. Further, to our present knowledge and awareness, these VS patients do not feel hunger or thirst, providing feeding care may then seem somewhat ambiguous.

#### 7.4 Terminal illness

Terminally ill patients, having no more than two weeks to live, have no use of ANH. They will not die later, even if one provides them this form of treatment. Therefore, withdrawing ANH, can be rightly done, following the normal medical procedures. A terminal illness can be transformed into a time of thanksgiving and bountiful graces for those involved; however, this does not directly concern patients who are in a vegetative state. A personal care, where the person is in direct personal contact with the care-giver and where someone is holding a hand, might be more efficient.

#### 7.5 palliative sedation

When other treatments seem not to relieve a burdensome and excessive suffering of an imminently dying patient, then Palliative sedation therapy (PST) is a valid palliative care option. De Graeff and Dean define PST in the following manner, in their article *Palliative Sedation Therapy in the Last Weeks of Life: A Literature Review and Recommendations for Standards*:

PST is defined as the use of specific sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness, using appropriate drugs carefully titrated to the cessation of symptoms. The initial dose of sedatives should usually be small enough to maintain the patients' ability to communicate periodically. The team looking after the patient should have enough expertise and experience to judge the symptom as refractory. Advice from palliative care specialists is strongly recommended before initiating PST. In the case of



continuous and deep PST, the disease should be irreversible and advanced, with death expected within hours to days. Midazolam should be considered first-line choice. The decision whether or not to withhold or withdraw hydration should be discussed separately. Hydration should be offered only if it is considered likely that the benefit will outweigh the harm. PST is distinct from euthanasia because (1) it has the intent to provide symptom relief, (2) it is a proportionate intervention, and (3) the death of the patient is not a criterion for success. PST and its outcome should be carefully monitored and documented (De Graeff and Dean, 2007, 67).

The recent development actualizes the need to distinguish between euthanasia and palliative sedation. The clear demarcation between palliative sedation and euthanasia is dissipating, caused by widespread puzzlement among clinicians about the meaning and significance of the ethical concept of intent. The standard position is that the decision to provide palliative sedation ought not to be the same decision as the decision to forgo life-sustaining treatment. To provide ANH will be futile or even harmful to patients in palliative sedation. Approaching the end of life, patients tend to drink and eat less than before. Research shows that when the life expectancy is less than two weeks, forgoing ANH does not hasten death. Otherwise, when the prognosis is two weeks, or longer, dehydration might hasten death. The tendency to combine palliative sedation with ANH in Catholic countries like Italy can be explained by the Church's insistence on the administration of ANH (Have & Jos, 2014, 131-132).

## 8. What else: Who is deciding?

This chapter will focus on who should make the final decision how long the artificial tube feeding and drinking supplies ought to be given: is it the doctors, the relatives or the patients themselves. These reflections will consider the problems with informed consent and with advance directives.

### 8.1 Autonomy

Some issues are decided in accordance with tradition, only by the individual's prudent judgment. It is hardly possible to legislate what anyone ought to do in particular, and choices will have to be left to individual conscience (Wildes, 1996, 503). Autonomy is an important value, and the expressed wishes of the competent patient must be considered in the beginning of the evaluation (Shannon & Walter, 1988, 644).

The principle of autonomy means that a person has control over one's life and its events, and some argue that within the autonomy claims it should be included the control at which time one will die; that a person can decide if one's life is worth living. It is not the family or the society that ought to be able to decide another person's values. To oppose the principle of autonomy would be an affront to this person's dignity. However, if the autonomy of a single person is of the utmost importance in deciding whether the person ought to be treated or not, it is not true that only one person is affected by what happens. The decision about ANH concerns not only the individual but the whole community, family and friends, and their interests.

The principle of autonomy implies that people are considering their decisions and think, speak, or act in accordance with that decision, as long as the individual is not at the same time harming another individual (Beauchamp & Childress, 2001, 63-64).

The principle of autonomy presupposes some free choices in life. It is questionable whether a person in advance is able to decide on a future that one cannot foresee. A person, suffering unbearably in the final phase of a disease is rarely really autonomous, making the principle of autonomy problematic. This person does not have an overview of their situation, which would require at all times being able to make good decisions or to

induce from several circumstances what is relevant and then determine what would conform to medical ethics, one's resources and opportunities (Fernandes, 2001, 386-389).

## 8.2 Respect for the patients will

Generally, a competent patient who has requested ANH is to have this request fulfilled. In Catholic tradition, the patient himself ought to decide whether to abstain from a proposed treatment or not. The free and informed consent of the patient, by which the patient is aware of the nature of the intervention, the benefits and risks and the efforts required to perform it and the possible effects is the normal procedure according to the Catholic moral tradition for medical treatments. Treatments are also permitted in emergency situations when there are no indications that the patient would oppose the medical intervention.

Meilaender states that "patients who are competent may rightly think about how much burden they want to impose on others" (1997, 530). However, the psychological pressure these patients may live with can be quite harmful on their liberty of judgement. When they are convinced that family does not want to visit them anymore, that the society would not like to pay for them anymore, and that commissaries from the health care organisation make advances with the scope that these burdensome old fellows terminate their life as quickly as possible: who would then be strong enough to continue to live? This might be a very theoretic problem for MCS patients who are barely aware of their surrounding people; however, there have been cases where the personnel has tried to interpret the signs of a patient thus, that the patient would have manifested a will not to continue to live. It would then be easy to move to a situation where a nurse or a doctor asks the patient if the patient is tired of being a burden to the society, the family and the hospital and interpreting gestures as an affirmative response.

## 8.3 Informed or presumed consent or permission

Informed consent differs from presumed consent. Presumed consent is used at the expense of people's right to respect for their individual freedom and moral autonomy, to

promote the advancement of science, or when an informed consent is not possible to get, due to the person concerned being unconscious.

Informed consent is an important part of medical ethics, where medical personnel inform the patient about the patient's health. This information usually is not exhaustive, nor does it always describe properly what the question is all about. A patient's lack of knowledge can be the natural cause for such a vague description. To then say that there is a real consent, because the patient has largely caught on, seems difficult to affirm.

The relationship today is among a medical team and the patient and the patient's family. Medical information is often technical and difficult for non-medical persons to understand. The information, which we may spontaneously imagine as personal, is rather more widely available. One finds oneself when one is sick in a weak and vulnerable position where one often is worried, and decisions are not at all easy to make. Is there any truly informed consent in such a situation (O'Neill, 2001, 689-704)?

Árnason proposes instead that people give their informed permission, a type of written authorization. An informed permission is more general than informed consent. It does not require a certain amount of knowledge to be able to consent, just as much as it is necessary to give the permission (Árnason, 2004, 41-45). This might be something for the advance directives of future ANH patients in a vegetative state.

#### 8.4 Advance directives

Advance directives can assist in the judgement of how to treat a patient in a vegetative state, but are not the solution to everything, and their worth may depend on when they were written and in what circumstances, similar or dissimilar to the situation where the patient is actually.

Advance directives often imply more questions to resolve than they solve: Are the advance directives still valid when the vegetative state occurs? How clear is the directive to be formulated; in what lapse of time? What happens if a family member has a later testimony contradicting the advance directive? How can you assure that the patient or the proxy is well informed of what it is about and what degree of knowledge is expected? Is there to be *clear and convincing evidence* that the patient in an unconscious state once

wished an end of treatment, and what does clarity mean in this context? Is it to be as precise as to at least once having expressed publicly: if one will end up as a VS patient one day, then one would wish the withdrawal of ANH, that is, when one's diagnosis has been ascertained, would one not? In the United States many of these concerns are dealt with through a *health care power of attorney*, a document by which one gives limited temporary authority to another person to act on one's behalf. The person with a debilitating health condition specifies in writing that the person, whom one designates as one's health care agent, can make decisions regarding one's medical treatment and health care ("The Scope", n.d.). However, one still does not know whether the patient wants ANH or not, only that the person once wanted an attorney to decide about it.

## 8.5 Proxies

If the patient is unable to respond, a designated proxy, usually a family member, may take the responsibility to grant the best interests of the patient. A proxy is useful, for one can assume they know what the patient desires, given their common humanity (Cahill, 1989, 114) and proximity to the patient. The family plays an important role in decisions, because the individual most affected by a decision often cannot participate directly. Generally, the family has a relationship with the patient and knows the person's wishes. The family is normally in the best position to discern the patient's wishes or desires. Thus, it can either relate what the patient actually wanted or, failing that, relate its best judgment of what the patient would have wanted (Shannon and Walter, 1988, 646). However, families can disagree and sometimes the family seems only to makes things even more difficult. Designated proxies are a more flexible option that adjusts and responds on the very moment something has to be decided. However, do they represent the patient himself? Families and near friends often have a very diversified opinion on what the patient would have wished to do, not reflecting only their proper views, but also the complexity of a person's beliefs. It is important to provide an as good as possible pastoral support to those facing stressful life-or-death decisions, and resolve hostility and conflict.

## 8.6 The responsibility of the doctors

Physicians can never be compelled to order interventions from which they expect no medical benefit, no matter how much the family insists on the futile treatment, especially so when the treatment is expensive (Cahill, 1991, 118).

It is the responsibility of the physician to judge whether a treatment is futile or not, disproportionate or proportionate to the benefits of the patient and the burdens of the intervention, to assure the assertion what the illness consists of and if there are possibilities of recovery (Ashley, 2006, 188, 191). The medical staff has a duty to respect the wishes of foregoing or withholding treatments made by the patients and the proxies within the limits of medical science and technological possibilities. The agents will in this case respect the will and autonomy of the patient more than causing the death of the patient.

Contrary to what is acclaimed here and there in moral literature treating ANH in relation to VS patients, it is here contended that ANH is basically a medical treatment and not only a basic care of feeding a person or letting this person drink. It is not so simple that once one hears the evangelical recommendation to feed the hungry, one is able to remedy the difficulties of a patient in Post Coma Unresponsiveness. The decision to use and the insertion of the tube to tube-feed someone necessitates a medical competence and training, sometimes even a surgery. The prescription of what the patient needs to eat and drink requires advanced dietary knowledge. How to best care for the patient and the surveillance of any aspiration problems, infections, or other side-effects are best suited to those who have medical and nursing skills. All this seems to be a medical treatment and not only a basic care of helping somebody to eat one's daily bread. A medical intervention may render it possible to do some parts of the care at home, when this is permitted by the law. Thus, ANH is not an option without medical professionals (Gómez-Lobo, 2008, 106).

## 8.7 Church authority

Conscience is often considered the ultimate subjective norm of morality corresponding to an objective norm given by the reality and of the revelation (for the persons of faith). Consulting authorities allows people to share the past experiences, the expertise and the leadership of wise persons. Following the guidance of an authority can

be a very humble thing to do, showing an awareness of one's limitation, as long as it does not undermine the duty to critically examine the facts one has at hand. In Catholic terms Church authority is labeled magisterium, and this has for at least two centuries been used practically exclusively about the hierarchy. Other people are expected to follow this teaching with an individual reflection and acceptance. They ought to have an openness and hopefully a disposition to believe that truth is in favor of the teaching (Overberg, 2006, 45). Everyone has to strive for a personal appropriation of the official teaching, so that it can be transformed from a religious submission to a personal conviction. One must also search to overcome possible contrary opinions one might have on the subject. Eventually one's adherence to a teaching comes from the trust one puts in the faith that the Holy Spirit assists and will guide the Church to a true and authentic stand on moral questions, even if it might take some time to arrive at that. The Church uses authentic stories and beautiful liturgy to form consciences. This formation takes time, and the Church can also make mistakes (Gula, 1989, 153-158. 203).

A Catholic has the possibility to disagree with the magisterium on some point of faith and morals, and sometimes things that were not according to church teaching become a part of it. There are some criteria for dissent including the differentiation of what degree of authority the Church bestows the contested teaching. The greater an authority is; the greater caution one needs to have and greater restraint with open criticism. A responsible dissent ought to be proportionate to the abilities, the authority and the insights one has to dissent in a certain field or with a specific ethical issue. An openly public dissent demands more competence than an interiorly hidden dissent. Finally, one has to be concerned that the church authority in general is affirmed, the means and the costs are fair, and the reformulation is clearly proposed (Gula, 1989, 207-214).

John Paul II addressed physicians invited by the Pontifical Academy for Life on 20 March 2004 to discuss care of PVS patients. This was not a document of the magisterial authority to the universal church and has to be comprehended in light of other statements from the same pope.

O'Rourke makes the difference between revealed truths found in the Bible that must be believed by the faithful; infallible teachings of the Catholic church regarding faith

and morals that also must be believed without a doubt; defined teachings, like e.g. encyclicals, explaining church beliefs in harmony with revelation and tradition that the faithful are committed to by a religious submission of the faith; and interventions to warn and illuminate the faithful in questions regarding both solid principles and contingent and conjectural elements. Since the address concerning ANH to PVS patients contains contingent and conjectural elements; i.e., those based on assumptions that are the result of incomplete or inconclusive evidence, likely to be true, but yet not certain, the statement of the pope on 20 March 2004 was not an infallible or definitive statement of Church teaching, rather it was an authentic or reformable statement (O'Rourke, 2008a, 165-166). The address may contain some deficiencies and formulations that could be better expressed.

#### 8.7.1 Canon Law

The CDF response, a singular decree on the liberty to use ANH, because it gives limitations to the free exercise of ANH, ought to be given a strict interpretation with respect to the matters which it decides and for the persons for whom it was given; in accordance with the rules of interpretation in the Code of Canon Law (§18, §54) and thus concerning only patients with a firm diagnosis of PVS (Hardt and O'Rourke, 2007, 45).

#### 8.8 The virtue of *epikeia*

The purpose of laws is to serve the common good and justice. Aquinas says that in some situations the letter of the law ought to be set aside in favor of justice and the common good. This decision to set aside the letter of the law is made according to a principle called *epikeia*, and with Aristotle, Aquinas calls it a virtue. *Epikeia* simply assures that one sees the purpose of the laws as serving the common good and justice; to follow the law will often be arduous and sometimes will have unpleasant effects and ought not to be overridden easily (Everyday Thomist, 2009). A practical, pastoral sense might sometimes dispense from the outcome of a sound although general moral argument and reasoning. The virtue of *epikeia* is used when the subject acting transgresses a rule in the spirit of the intentions that the lawgiver had once he established the rule. It is not only a



virtue that the lawgiver can use for his or her personal use. Aquinas expresses what the virtue of *epikeia* is in this way:

since human actions, with which laws are concerned, are composed of contingent singulars and are innumerable in their diversity, it was not possible to lay down rules of law that would apply to every single case. Legislators in framing laws attend to what commonly happens: although if the law be applied to certain cases it will frustrate the equality of justice and be injurious to the common good, which the law has in view. Thus the law requires deposits to be restored, because in the majority of cases this is just. Yet it happens sometimes to be injurious, for instance, if a madman were to put his sword in deposit, and demand its delivery while in a state of madness, or if a man were to seek the return of his deposit in order to fight against his country. In these and like cases it is bad to follow the law, and it is good to set aside the letter of the law and to follow the dictates of justice and the common good. This is the object of "epikeia" which we call equity [...] *epikeia* is a subjective part of justice; and justice is predicated of it with priority to being predicated of legal justice, since legal justice is subject to the direction of *epikeia*. Hence *epikeia* is by way of being a higher rule of human actions (ST IIa IIae q. 120 a. 1-2 in Aquinas, 1998 [1947]).

## 8.9 Social justice

It is difficult to achieve any distributive justice in trying to apply ANH to patients in vegetative state. The justice goal is more a certain "fairness" where the "moral action is the fair action that treats each person as equal to all similar persons in similar circumstances" (Schwartz et al, 2013, 3). Subject to discussion is the availability of medical staff to care for the patients, that might limit the ability to manage and monitor feeding, financial concerns and the specific site more or less adapted to such treatments.

An overall consideration whether a treatment given to one patient would be fair in comparison with other patients, may help to arrive at a sound judgement whether the treatment is proportionate not only to the harms of the intervention itself, but also to the extension of harmful side effects like nausea and several inabilities attached to the postoperative condition.

It would be an ideal if hospitals, parishes, schools, and helping organizations could integrate in a common comprehensive program of healthcare (CHA, 1993, 51). John Paul II suggested the following concrete practical ways to help:

...the creation of a network of awakening centers with specialized treatment and rehabilitation programs; financial support and home assistance for families when patients are moved back home at the end of intensive rehabilitation programs; the establishment of facilities which can accommodate those cases in which there is no family able to deal with the problem or to provide 'breaks' for those families who are at risk of psychological and moral burnout (John Paul II, 2004a, in May, 2005, 553).

Pope John Paul II is giving a recommendation how to act, and when the circumstances are not further specified, then one ought to give ANH. This text reflects the thought that a decreasing probability of a possible recovery does not ethically justify the cessation of ANH. Consideration of the quality of life does not have any effect on the obligation of ordinary care, which always remains an obligation (Degnan, 2008, 39). Probably is it the dignity of the person and the firm will to protect human beings from the atrocities of what happens in wartimes that influenced the pope to take these further measures. There are however, circumstances in accordance with Catholic moral tradition, when this recommendation will not be valid.

An objective criterion is the expense of the treatment and whether one can afford the treatment or not; what is discussed is rather who ought to pay for the treatments, the patient, his family, friends or maybe the community through its medical care. Whether the treatment requires an investment in personal and technical efforts proportionate to human efforts or not is a decision taken by the hospital and its medical staff. To avoid arbitrariness in the health care it will be better in critical moments to develop detailed guidelines what to do in difficult situations and have an ethics committee to apply them in the actual moment. A treatment can imply an inequitable allocation of social resources, and this discernment is political and ought to be scrutinized remembering the principle of the common good (CHA, 1993, 50). Cahill finds that one ought to respect those patients who for reasons of social justice would not like to access the highest levels of medical technology (Cahill, 1987, 123).

Often the law of a state is supporting that ANH is a medical treatment that can be forgone like any other treatment. Sometimes there can be a court decision regulating what is to be done. Contrary to what is often sustained by an autonomous ethos a person is not qualified by one's independence and freedom to do whatever suits this person, but rather by one's interdependence. A vegetative patient can be left to one's isolation and self-interest; however, the patient is of concern to others than himself or herself: the family, the caregivers and the community. The virtues of solidarity and love for loved ones can be showed to the patients by allowing them to die and praying for them when life support is no longer beneficial (O'Rourke and Norris, 2001, 204).

The ethos of individualism that is dominating the contemporary Western healthcare and philosophy can be replaced by a healthcare governed by the ethos of interdependence, where interdependent relations would be sustained by trust and honesty (CHA, 1993, 49). "A disproportionate amount of healthcare resources are expended on relatively expensive care for a small population which stands to benefit relatively little" (Cahill, 1991, 126). Many disadvantaged groups cannot access care, due to income, race, ethnicity, age, disability, and global location, and women more frequently are excluded. This inequality and deprivation plague access to health resources worldwide. To change this situation should be the first priority of any bioethics worthy its name (Cahill, 2006, 139, 142).

It could be argued that considerations of distributive justice, responsible stewardship, and the common good would require dedicating our health-care resources first to rectifying some of the fundamental inequities in the current structure of access to health care in this country [and others], before dedicating any resources to 'awakening centers' that may or may not have any impact on outcomes (O'Brien, Slosar, & Tersigni, 2004, 504, 511).

The need of reflection on poor financial aid and the discernment of priorities is evident: a hospital bed may seem a human right; though, it requires solidarity and care. Often, it is complicated to decide who ought to decide and that there is an interaction necessary between the various parties, frequently composed of several individuals or teams. It will soon be clear that the decision is not given in advance, nor is it easily taken.

## 9. When to forego and when to withdraw — is there any difference at all?

When one has only the proportions between the involved persons' burdens and benefits in mind, then there is no difference between withholding and withdrawing treatments that are futile or excessively burdensome for the patient. However, it may feel more awkward to withdraw a treatment than to forego the same treatment, since the death might be an undesired consequence from such a withdrawing of the treatment and therefore the hope of recovery is lost. The proper cause of death; however, will be the fatal disease and not the foregoing or withdrawing of ANH. The medical act of letting the patient die ought not lead to holding the medical staff responsible for the death of the person (CHA, 1993, 50). ANH

has negative effects and few benefits for some patients, especially the frail elderly. Besides inability to assimilate the fluids and consequent bloating, effects include mental agitation, irritation, infection, bowel perforation, diarrhea, cramping, nausea, vomiting, blockage and leaking of the tube (Cahill, 2006, 127 from CCBI, 2004, 780).

The intent of withdrawing or foregoing ANH to VS patients is not to deny the value of a person or to make a judgment of this person's social, economic, biological, or spiritual worth. The intent is to recognize that medicine, the treatments, and the interventions it can offer have limits, and that further care will be burdensome, hopeless and of no use (Shannon, 2008, 914).

The decision to withdraw or withhold treatment is not a decision to end life, but a choice not to preserve it because the emotional, psychological, and spiritual cost of preservation is too high. This is a decision by a patient or a designated decisionmaker about the quality of life. It is not made by some social standard, but by seeing the life and the treatment in the context of one's relationship to God (Wildes, 1996, 511).

### 9.1 Excessive over-zealous unreasonable obstinacy

*Unreasonable obstinacy* translates two French words corresponding to the English concept of futility. The French Leonetti Act of 2005 specifies how medical care should be carried out in France in the final stages of life. The law prohibits excessive obstinacy

regarding examinations and treatments. The Act authorizes foregoing or withdrawing a treatment when it is useless, disproportionate or has no effect other than to artificially maintain, conserve and preserve life. Analgesic drugs may be used, even in cases where there is a risk of shortening life. The Leonetti Act encourages the search for consensus, the choice of options, frequent mutual discussions between caregivers and between medical professionals and patients with their relatives, and an enhanced palliative care. The main change the Leonetti Act introduced is the possibility for physicians in France to withhold or even withdraw life support for unconscious patients (Baumann et al., 2009).

## 9.2 Futility

The futility of a medical treatment is to be decided by medical doctors. A medically futile treatment is a medical intervention or treatment that might be physiologically effective, but cannot be of any other benefit to the patient (Drane and Coulehan, 1993, 31). When a treatment is futile, it is not conforming to the goals of a medical intervention or not benefitting to the general condition and personal good of a patient. This ought to be decided by the physicians, and it ought not to be proposed to the patients when it does not alter the patient's condition or state of consciousness, or does not ameliorate the patient's respiration capacity, the relationship capacity, nor the patient's autonomy or independence. To implement such decisions one needs medical interventions and the knowledge of these interventions relation to medical goals (Drane and Coulehan, 1993, 30). Even if a treatment really would be futile, one is nevertheless permitted to receive such a treatment; however, it might be regarded like a waste of resources, time, money, and labor, and might have some harmful side effects.

It would be wrong to label ANH as futile, when one has in mind the pursuit of full recovery or of consciousness and that is not attained. Then, it may be an inefficient means; however, not a futile means. The ANH provides a continued biological existence to patients in a vegetative state, and may yet be inefficient to what proxies and medical staff desired would be the outcome of the therapy. ANH may help the patient to maintain or at least continue organic existence without reaching the consciousness and human vivacity the patient once had.

### 9.3 Imminently dying

Is it really a clear issue at what point one is dying? One could argue that one is dying all the time, even if one does not feel it in this moment. When does a state become terminal and when is one imminently dying? It seems an ambiguous expression that often is dependent on the technology available at the moment.

For imminently dying people, the body loses its potential for recuperation. Medical treatments become less effective. The pains increase. Burdens become proportionately greater with declining benefits. One calls a pathology refractory when such pains do not respond to all available medical treatments.

It follows from these reflections that the decisive factor is not the material nature of the symptoms but their refractoriness. Compared with psychological and, even more so, existential suffering, it may be easier to ascertain that, and when suffering rooted in somatic pathology is refractory, that is, when such pain fails to respond to all available drugs and other physical therapies. But the morally relevant factor here is not the source of the suffering but its refractoriness (Have & Jos, 2014, 130).

The refractoriness is then not the illness in itself, but the non-responsiveness to the cure. ANH might be a difficult case to judge: ANH provides a continued biological life, in that way the person responds to the medical treatment of ANH; however, the patient may nevertheless not respond to the medical treatment for the illness causing the unconscious state of that same person, and the illness can after a while be judged refractory. VS patients breathe, sleep and are awake with eyes open, they respond to light, and normally have a gag and cough-reflex intact. There are no established medical criteria deciding who are those persons included in the group of VS patients, like there is a criterion for brain-death, which is well defined for that group of patients. Surviving for several years is not uncommon among VS patients. Survival depends on ANH, "age, economic, familial, and institutional factors, the natural resistance of the body to disease and infection, and changing moral and social views of this condition" (Shannon & Walter, 1988, 633).

A question to ask is whether ANH provide the body with the nutrients and fluids necessary to sustain and heal the body. Clearly ANH prolongs the biological life compared

to a VS patient left alone without ANH. However, if this sustenance is effectively given, there are also signs that VS bodies deteriorate due to aging and perhaps the situation they are in. It is thus important to find out whether sustenance contains many flaws and if one can speak of any healing at all (Valiquette, 2008, 558). The patient is sustained and continues to live, but in many aspects ANH seems to be insufficient and does not provide any healing over time.

Another question is if the ANH provides any relief from hunger and thirst. Strictly speaking, VS patients might not be conscious of these feelings and persons today are certainly unable to understand the signals they might communicate. What one does know is that in several studies patients with end-stage cancer reported experiencing minimal hunger or thirst (McCann RM, Hall WJ & Groth-Junker A, 1994, 1263-1266) and the hydration level seems not to be in relation with the feeling of thirst expressed (Ellershaw John E, Sutcliffe, Jane M. & Saunders Cicely M, 1995, 192-197). As far as most medical research can discern, withdrawal of ANH from patients in VS does not cause any change in pain level for the patient. Cahill argues convincingly that it seems that there is little substantial public scientific evidence supporting the likelihood of diagnostic errors or the argument that withdrawal of ANH always causes suffering (2006, 127).

#### 9.4 Omissions

There is a difference between justified omissions and unjustified omissions. In some situations, there is a responsibility to provide life support. If one person has had a serious car accident, anyone who passes by has a responsibility to do something: call an ambulance and, if possible, try to give life support. For the community and the society to do nothing would be an unjustified omission. If nobody came by within the first four days after the accident, anyone who passes by will nevertheless have a responsibility to do something, would it be only to call an ambulance and the police. Otherwise, it would be an unjustified omission. In a similar way, within a year after the patient had been rescued from a car accident, it would be an unjustified omission to leave an unconscious person without the support of ANH. However, after this year in hospital, and the physicians have concluded that one has been, is and will be in a vegetative state, according to present

scientific knowledge, then not giving ANH and letting the illness have its course, would be a justified omission, because the burdens outweigh the benefits, according to the proportionate way of reasoning, used in this thesis.

The result of this investigation of when to withdraw or forego is that when the condition of the patient otherwise is not too burdensome, nor a condition of someone who is terminally ill, a patient ought to have been stable in a vegetative state for at least one year, and that the doctors involved judging the health of this patient ought to agree that the patient is in a vegetative state and nothing else. If treatment continues for a longer time than a year, when every future possibility of an improved condition of health can be excluded and there is no hope of benefits outweighing the burdens, then the medical treatment has become disproportionate to the patient's condition.



## 10. Where is the main point?

This chapter will summarize some of the important facts stated so far about the value that life has and what health care is proportionate to that value. This will ground a better discernment analyzing the moral cases in the next chapter.

### 10.1 Physical and biotechnical improvements or an overall condition of health

Medical care at the end of life is often driven by technological advancements. Frequently, it seems inappropriate to begin a life-sustaining therapy, when death can soon be expected. There is a development to decrease admission of these patients to intensive care units, and to give them a better planned and augmented specific palliative care. There are cases when ANH hastens death and is not in the best interests of the patient (Laing, 2008, 84). McCormick concludes that for patients in a vegetative state who are irreversibly comatose the presumption ought to be against treatment (Cahill, 1991, 109). For the vast majority of dying patients evidence shows that burdens and risks of ANH at the end of life far outweigh any likely benefit, states Coyle and Todaro-Franceschi and they insist on the importance of communication:

Early communication between patients, families, and the health care providers about the benefits and burdens of ANH at the end of life is important. Such discussions will help clarify the patient context, including culture and spirituality, often expressed through values, beliefs, goals, and aspirations. These conversations can be especially difficult if held for the first time when a family is struggling to accept that death of a loved one is near, and that ANH will neither prolong life nor improve comfort (2012, 93).

When one speaks of quality of life, there is a sharp difference between biological life and personal life. The physical and biological life is worthy and immensely precious, and not at all conditioned by any property or characteristic of the individual. The biological life is a real, true and high value, though created and therefore limited and deficient. Every physical life is therefore of equal value. The quality of life ought not refer to a property or

attribute of life. It refers rather to the quality of relationships between the medical condition of the patient and the patient's ability to pursue life's goals and purposes.

The structure of the actual moral obligation is teleological in that the patient's condition is always viewed in relation to the pursuit of life's purposes, and the grounding of the obligation always involves an evaluative assessment of the qualitative relation which exists between these two components. (Shannon & Walter, 1988, 636).

The sanctity of life remains an important pillar in a deontological line of thought in the framework of defending the human person. Would a quality of life judgement in a proportionate reasoning that sees to the benefits of the patient and his or her potential burdens resulting from a medical treatment then be inappropriate?

Technology is a helpful means, but a means that can be reduced by larger considerations of the integral reality. Just because one can do something, one ought not do it in every occasion. One cannot infer an actual moral obligation from the mere possibilities of the technology. It is not the technique to solve a problem of health that is important, it is the health of the whole person, centered on the person treated that is extremely important to keep in mind. The treatment ought to be given considering all its aspects in proportion to the benefits of the person treated, this person's overall condition and this person's goals of life. The technology has not yet been proven to ameliorate a patient's general clinical condition when in a vegetative state nor restore this individual to any state of health where the patient might pursue the values of life.

There is a time when one does not know the issue of a treatment or the diagnosis of a patient. Then, it is indeed appropriate after necessary treatment to preserve the post-traumatic life. After a while, sometimes sooner, sometimes later, when one, aware of what is available, knows that one has done the best one can do and there is no hope to reach a better health for the patient treated, then the efforts of caring cure ought to change to a palliative accompaniment of care, respect and compassion preparing for acceptance of the proximate death of the patient. It is utterly important to become aware of when it is time

to finish further treatments, if we want to avoid that people might be afraid to even begin them in situations where this treatment really may help the patients. Being clear with this from the beginning might help families not to feel heartlessly disappointed nor trapped in a medical treatment, often helpful, but limited.

The problem with restricting too much the criteria for when it is possible to withdraw ANH from VS patients, for example restricting it to when ANH "offer no reasonable hope of sustaining life or pose excessive risks or burdens", is that this makes biological life an incommensurable good (cf Germain Grisez). This does not take into due consideration the natural inclination, longing, and desiring of the human being to live, not only the biological life but a life exceeding the biological sphere made out of true human relationships between historical persons with a character and identity, living in joy, happiness, fulfillment and peace within the communion of God and love of the neighbor, clearly with some ability to function at the cognitive-affective or spiritual level and striving to reach this purpose. (O'Rourke and Norris, 2001, 203, 207).

## 10.2 Curing

To cure a patient is to heal and reestablish a patient to the maximized good health possible. This is often the intuitive and immediate goal of all health care. It remains like an unreflected presupposition to everything that is done within the health care institutions.

ANH is only one aspect of the care given to the patient. To have a holistic overview of a patient in a vegetative state one will include other aspects such as medications, antibiotics, treatments, supplementary oxygen, sustaining organs with rather complex methods like resuscitations, and the administration of blood transfusions (AAN, 1995, 1018).

## 10.3 Caring

Curing is not everything in health care; sometimes it is good to change the perspective from curing the patient to caring for the whole person. When a person is imminently dying hospice care can offer a caring hospitality respecting the integrity of the person and establishing relations between the dying person and his or her family and

friends (CHA, 1993, 49). Caring embraces, at least for conscious patients, dimensions like participation, empathy and meaningfulness and can be expressed in the act of keeping someone company. Caring is more of a presence, to listen carefully the life-stories acknowledging the values of living, whether these stories are really expressed or only felt and bear the burden with the patient sharing his or her life for some precious moments. It is a comfort to easier bear the burdens of a treatment, especially if they seem to go beyond one's capacity. Caring does not replace the cure, it is a necessary complement to the cure and respects the fact that human beings are spiritual and material bodies altogether. A caring hospitality given in hospices considers the many aspects of the patient's general condition and this person's goodness, trying to ameliorate the conditions of dying by reaching the many people acquainted with the patient in an intimate conversation of friendly support. (CHA; 1993, 49, 51-53).

Would it be possible to still give care to a patient, once one stops feeding this person? One reason claiming this possibility is that the relational care is not bound to a certain way of humane caregiving. One might tenderly love and care for a person without wanting to feed this patient artificially. Not prolonging life by ANH is to permit a life to end, yet that is not equivalent of thinking that a life is not worth living.

The question is not whether VS patients have rights or deserve care, but what treatment respects their dignity best and serves its purpose in the most appropriate fashion. Families and caregivers must determine the best interests of the person affected who has virtually no potential to regain consciousness by reasonable medical standards (Cahill, 2006, 127-128).

#### 10.4 A person's human condition

Certain qualities of life corresponding to objective needs may rightly influence the judgement not to give ANH to VS patients and is not purely utilitarian calculations of the value of life. A help to avoid this deviation is to determine relatively objective criteria when a need is sufficient to cease ANH in accordance with the due respect and care for the dying person; for example, when the sufferings are severe and irremediable, and of a physical nature (Cahill, 1991, 124).

To distinguish what a person's life is and what that person's physical life is can help in this context. To be a person is not only to be a living being; it is to be a person having relationships, having an identity and a historical background. Quality of life then, to restate the argument of Shannon and Walter, are proportionate relationships between the medical conditions of patients and their respective ability to reach the goals and purposes of life. Thus, the medical conditions are conditions of physical life; yet not only of physical life; they are also related to spiritual life, because the spiritual life of a human person and the ability to reach one's purposes of life are in some ways conditioned by the health of that human person.

There are values transcending physical life and social accomplishments. The value of every person is founded more profoundly on a relation of love than on a claim of equal and unconditional justice. The question is whether the treatment enhances these values in the life of the patient or is a burden in anyway to reach them. To be a person is not equal to being able to consciously communicate, although the loss of individual rational communication might be one (not sufficient) sign or criteria that the person is dying. The criterion of dignity does not help us here. The ideals of what a dignified death is can be viewed in so many ways. More helpful is the criteria of physical disintegration and of ability to consciously love someone or seek a higher spiritual good. Cahill points out with McCormick that if there is no "reasonable hope of pursuing life's purposes at all" or if these purposes are achieved only with "profound frustration or with utter neglect " a treatment is not justified. Then, there is not a proportionate reason to continue the intervention or the treatment (Cahill, 1991, 118).

The following chapters will give an analysis and some advice on how to ethically evaluate the three moral cases, which were presented in chapter three and what one ought to do and then provide a summary of the master thesis' results and resulting challenges.

## 11. Advice to the persons involved with the three cases



Image 6: Ms Aruna Shanbaug,  
<http://www.mirror.co.uk/news/world-news/aruna-shanbaug-brain-damaged-nurse-5716134>  
The journal has no copyright on this image:  
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### 11.1 Aruna Shanbaug

Ms. Shanbaug never woke up from her unconscious state. Her injuries were of a physiologically non-traumatic nature, caused by suffocation and anoxia, requiring only six months instead of one year for physicians to tell that she will probably never wake up. In contrast, the attack itself with rape, strangulation and severe blows was sufficiently traumatic that there is reason to wonder if she were suffering from this trauma during her illness. Nurses reported that Ms. Shanbaug shouted as they approached her. This led the nurses caring for her to conclude that Ms. Shanbaug had a certain sensation of her surroundings intact, implying that Ms. Shanbaug was not in a vegetative state, but in a minimally conscious state. However, it happens that patients in a vegetative state scream, and that the screaming is not related to the presence of the nurse. If the sensation has anything to do with a sensation of someone approaching the patient, then this can be due to the psychologically traumatic experience Ms. Shanbaug had just before entering an unconscious state, thus, resulting from anxiety and post-traumatic stress. The question is then if Ms. Shanbaug were continually psychologically suffering during her unconscious period of life. If Ms. Shanbaug were in a vegetative state, as seems to be the most probable alternative, then she would not have been able to suffer during her unconscious condition; were she, on the contrary, in a minimally conscious state, then she might have suffered on a very basic level.

There is no information that Ms. Shanbaug wished to remain continually treated with the ANH, nor that she wished it would stop. What is known is that for those caring nurses in Mumbai Ms. Shanbaug became a symbol of the abused women and nurses in the contemporary Indian society. Does not the patient's disadvantages outweigh the advantages for her environment? It could be considered a benefit from the fact that she was still alive, as a symbol of the injustice they wanted to eradicate. However, an individual's needs should be given priority over the related parties' needs and desires.

According to what appears in the archived pictures, Ms. Shanbaug became increasingly emaciated by the years. Surely aging affects even unconscious patients, but it does not seem as if it is the only explanation. The question then is whether the nutrient has been insufficient in any respect or if the deterioration resulted as a consequence of a being held alive with artificial nutrition. Another question is whether a perduring treatment always involves some physical suffering. If Ms. Shanbaug cannot suffer, which seems to be what science is inclined to adopt today, then one wonders if it were right to continue to nourish her, if she might have been continuously underfed and therefore did not maintain weight, despite the efforts of the dietists, or if it would have been better to end the ANH.

Ms. Shanbaug's family did not take care for her some years after the injury that caused the unconscious state. Probably, they could not afford the treatment. When the family was no longer interested in taking care of Ms. Shanbaug, the choice of a legal representative, some sort of attorney of public health, seems to be a good option.

The advice, which seems most reasonable to provide for those responsible for Ms. Shanbaug's well-being, is that they let her die, after they had been scientifically assured and that they were as certain as possible that she would not wake up again. Ms. Shanbaug's burdens resulting from her physical and mental conditions seem to be so severe that they were not outweighed by the conditions of life Ms. Shanbaug would have through the ANH given by the nurses.

The moral case was complicated by the fact that the life of Ms. Shanbaug became a symbol of nurses' rights and even more complicated by the request to allow passive euthanasia. This in the minds of many people was equal to allowing euthanasia in India, something that would have been far away from the real intentions, if not of those

requesting passive euthanasia, at least regarding the judgement of the moral case in this thesis. However, here it is not a question about euthanasia. Passive euthanasia is not at all a form of active euthanasia where one is letting the doctors kill the patients.

Ms. Shanbaug was unable to experience and fulfill the purposes of life. She could not experience the joy of exchanging ideas, states of mind and feelings with other persons in a mutual dialogue made out love and respect, thus maximizing her human freedom and creativity. The deterioration of her physical and maybe of her psychological conditions indicate that the treatment was contrary to the best interests of Ms. Shanbaug, the medical support having reached its own limits of what it could do to help her. The total pain and the deteriorating condition of Ms. Shanbaug were motives to stop the once ongoing treatment. Probably Ms. Shanbaug was never conscious during her rather stable VS. Therefore, the advice to let her die by the natural causes of her illness, seems to be well founded (see 4.5; 5.5; 6.8-6.8.3; 7.3-7.6; 8.9-10.4). Letting Ms. Shanbaug die would not have been an immoral omission.



LE CONSEIL D'ÉTAT VALIDE L'ARRÊT DES SOINS

# Le combat pour Vincent Lambert

Paris Match | Publié le 23/01/2014 à 18h59 | Mis à jour le 24/06/2014 à 17h12

Arnaud Bizot



Au printemps 2013, au CHU de Reims. Une parente de Vincent, tente d'établir le contact grâce à un dessin.



Image 7: Mr Vincent Lambert,  
<http://www.parismatch.com/Actu/Societe/Vincent-Lambert-Condanne-a-vie-545453> The permission of the journal excerpt granted by the journal.

The major challenge in this case is that Mr. Vincent Lambert's condition is difficult to assess. The doctors do not seem to agree what degree of unconsciousness Mr. Lambert is suffering from nor whether to interpret Mr. Lambert's different expressions and gestures as conscious or not. There is currently a dispute about whether Mr. Lambert is still in a minimally conscious state or in a vegetative state. Giving a moral counsel in this case will depend on one's interpretation of whether Mr. Lambert is in a vegetative state or in a minimal conscious state. If Mr. Lambert is in the MCS, then the situation may evolve and he might become decisively better than he currently is. Since the doctors have made different assessments over time, it may also be wise to see how this uncertain prognosis evolves. If instead Mr. Lambert is in a vegetative state, then it is probable that he never will wake up to a conscious life again on earth. After a year in a stable VS, the probability

that the patient will wake up again is close or equals to nil. However, it is very difficult to discern whether someone is in a stable VS.

It seems probable that Mr. Lambert is in a VS, due to the fact that the medical staff most closely involved in the maintenance of Mr. Lambert of the hospital in Reims make this judgement, which has been the same for a few years now. The impression is that the medical staff at the hospital of Reims is quite unanimous in its judgement. The moral advice based on this medical opinion would be to withdraw ANH and let Mr Lambert die.

There are a few medical professionals opposing the withdrawal of ANH. Generally, the credibility of the interpretations of Mr. Lambert's gestures and statements can be questioned and are contradictory. The doctors seem to interpret the patient's gestures accordingly whether they want to continue or stop his treatment. So it is just an interpretation of several possible interpretations to express with very unclear reasons and arguments an opinion, both if this opinion is that one wants to continue Mr. Lambert's treatment or if one wants to stop it. To assert that there is no conscious expression by Mr. Lambert, and to assume that he by his reluctance and his grunting wants to die: that is contradictory.

It is a problem that medical and court decisions may contradict each other and that this leads to such dire consequences for the patient. Mr. Lambert has been without ANH, repeatedly for too long periods of time, only because there are no clear regulations to follow. If the doctors must consult the whole family, this must be clearly stated. A part of the family seems to be convinced that Mr Lambert is communicating with them, and if they are not entirely convinced of that, at least they are thoroughly opposed to any withdrawal of ANH, because they do not think this is ever a morally good option. A withdrawal would thus go against their feelings and beliefs. Considering pastoral reasons, and not the morality of the case, and considering those who are weak in their faith or in their moral reasoning (cf. 1 Cor. 10), the counsel to give could be to wait until it is certain which degree of unconsciousness Mr Lambert really belongs to and whether he will ever be able to communicate or wake up again. Once assured that Mr. Lambert will not be able to regain consciousness again, one ought to pastorally encourage the part of the family which is opposed to stopping the treatment that it would be morally better to allow him to

die and that a continued treatment would not be without risks and the prospect is probably a weaker, more deteriorated health.

The patient's health is always a priority over family members' claims. However, in this case there are too many insecurities how to judge the case, that considerations of the family may be taken into account. If there is an option that the people caring for the cure of Mr. Lambert themselves can take care of and provide for Mr. Lambert's continued treatment, then they would be able to prove their concern for Mr Lambert and show their faith with merciful actions. An ordinary person is probably unable to provide this care that Mr. Lambert is in need of without an appropriate medical training. Therefore, the recommendation whether to continue or discontinue treatment appertains to the doctors. The decisions taken so far by the doctors who were favorable of withdrawing ANH to consider the views of the parents, against these doctors' own conviction that it would be better to discontinue treatment, seem to be very respectful of the weakest part of the family that needs more time to accept the situation of Mr. Lambert. The advice would be both to continue to give more information to help the family to make the right decision and to respect their concerns about removing ANH. As long as some medical professionals state that Mr. Lambert is not in a VS, the possibility of an amelioration cannot yet be totally excluded, even if a majority of the physicians would be leaning to that opinion or are of that opinion.

Mr. Lambert is not enjoying the spiritual, intellectual and free aspects of a human life. It seems to be a good idea in this case to complement the pastoral instruction with a deeper reflection in systematic theology. Some of the problems can be connected with a pro-life way of reasoning connected with a very traditionalist expression of the Catholic faith that would correspond to a vitalist attitude: save the life at all costs; no effort is too little in the battle of saving the souls; or maybe that death is a punishment from God that one has to avoid at least if one has not yet received the last sacraments of faith.

Were one to compare the state of Mr. Lambert to the six criteria of Rahner of what constitutes a human life, Mr. Lambert is a living body, with no spiritual exercises and no manifest conscience, probably with no social interactions. Even if this is disputed by some people, one can state that his social network is very diminished. He is a very unique

person with no freedom, that is, Mr. Lambert fulfills two out of five criteria on a human life. He does not have any possibility to engage in the divine exchange between God and human beings, and can, if he is in a VS, which seems to be the most likely description of Mr. Lambert's situation, only receive all the graces God bestows on him.

The social implications and consequences of letting Mr. Lambert die or remain alive are also attached to the symbolic value he has gained in France's pro-biological life or pro-human life groups. The parents and the new pro-life friends would be devastated if their son would be detached from the ANH; this aspect is important and cannot be ignored in a comprehensive judgement. For some members of the family and these new friends every measure of treatment would not be enough and indeed would be very proportionate. However, the opinion of Mr. Lambert's wife must also be taken seriously. She is in some ways dependent on the condition of her husband, if she is to rebuild a new family and give her daughter, already put to the test, a new family life. Ms. Lambert would only falsely be accused of abandoning her husband, or murdering him. On the contrary, her purposes and intentions seem to be good and decisions wholehearted, pure and good. She can thus be considered as the person most involved and the closest to Mr. Lambert.

There are rarely any clear boundaries between VS and MCS patients. Certainties about who is a VS patient are very difficult to reach. Mr. Lambert is sometimes awake and most people would say that he is unaware of what is happening around him. Some people and even a few medical professionals do not agree. One can at least establish that Mr. Lambert is unaware as human persons normally are aware of what is going on around them and that his interaction with people around him is clearly diminished.

Can the society put all VS patients in appropriate care, according to the wishes and vision of John Paul II? This thesis has questioned the economic feasibility and fairness of such an action. This thesis points out that according to tradition it is an act of faith and confidence in God to be able to let people die, when the hour has come, and that a continued biological life is a fundamental but not an absolute good that under some conditions ought to give way for what is more in harmony with the purpose of life. It seems quite clear that the discussions on whether ANH ought to be given to patients in VS

are clearly influenced by the biases of vitalism and utilitarianism in the contemporary society, also in a milieu, like that of Mr. Lambert that seems to remain rather Catholic.

Further treatment seems futile, even if Mr. Lambert is not terminally ill in the sense that with ANH he would not have more than two weeks to live. It does not seem possible to ameliorate the health condition of Mr. Lambert. He does not actually have a life fulfilling the purposes of a human life. There are contrasting opinions whether Mr. Lambert can feel any pain; however, it is possible to accompany him until the end with palliative sedation.

Many people are concerned of how the story of Mr. Lambert will end, and some of them seem to have a particular importance and ought consequently have something to say. First, Ms Lambert who shared the life of Mr. Lambert the last years of his conscious existence and who would naturally be the person who one would think knew the best what Mr. Lambert thought about being a VS patient. Then the parents are deeply affected by what happens to their son and who ought to be listened to and then the siblings and other relatives in a still minor proportion. As the family cannot be united in what to do with Mr. Lambert a possible solution would be a legal or medical representative chosen by the society. However, even the medical professionals and the church authorities in this case have conflicting opinions of what one ought to do with Mr. Lambert. This is a sign of a diversified society and shows that the statements of the CDF from 2007 can be differently interpreted. The question of who ought to decide is very complex in this case. The recent decision to make Ms. Lambert, Mr. Lambert's wife, the main person responsible for Mr. Lambert with the help of the medical personnel seems to be a fair solution.

### 11.3 Terry Wallis



Image 8: Mr Terry Wallis, <http://arkansaslife.com/reconnecting-terry/>  
Sara Reeves for Arkansas Life magazine

In accordance with the contemporary general recommendations and standard practice, Mr. Terry Wallis was counted as terminally unconscious after a year had gone by in a minimally conscious state. Over thirty years ago, one was admittedly not as well versed in the different degrees of awareness of unconscious states as one is today and one was unaware of the criteria which actually form the basis for such an assessment. A vegetative state was something more general and unknown. An important feature in Mr Wallis' story is that he was mis-diagnosed and the lesson seems to be that one cannot be certain, at least not yet, that someone is in a vegetative state until the autopsy of that same person.

Today, Mr. Wallis can be grateful that medical practice did not follow doctors' assumptions thirty years ago and withdraw ANH. The case demonstrated the uncertainty that still prevails in this part of the health care system, but also of the need to try to obtain better data for more accurate estimates in the near future.

Mr. Wallis today lives a life that is so precious to his family and caregivers, but still involves heavy sacrifices for the family and there are several difficulties to communicate. Sometimes, Mr. Wallis appears rude, intrusive, or hurtful in his choice of words. Mr. Wallis lives a dignified life. He manifests the love, care and joy of life, which are some of the key elements of a good life. Despite great difficulties, it seems like Mr. Wallis certainly lives a

life worthy of a human being. His burdens do not seem disproportionate, nor excessive in comparison with the benefits of his family enjoying being together.

In this case, it was worth waiting and hoping for an improved scientific knowledge about how the brain nerves can develop and complement each other and fulfill the destroyed nerve cells functions, even if they were originally located in a different place in the brain. The lessons that can be drawn from this case: be certain of a patient's condition, before taking life-ending decisions; use new technology to diagnose as accurately as possible; acknowledge however that cases like this one have been rare in the past decades. It would not be ethical to let this case inspire unreasonable hopes for other families having an unconscious member on ANH. It is worth remembering that a re-awakening and human re-flourishing is not always a return to a normal life, but can include many burdens for the patient and the patient's proxies. In this case, the other illnesses are bearable for the patient and the cures and care are indeed proportionate to these rather light burdens. It might however not always be that way. Another great value of this moral case is that patience and waiting may be rewarding: it is always better to postpone a judgement, than to make a hasty decision. Consciousness can be regained, and human life can be reborn.

## 12. Conclusion

This chapter will summarize some of the insights that this master's thesis has presented and then highlight some of the problems that would need to be studied more closely.

### 12.1 Summary

Contemporary research provides clearer ethical guidelines for when to provide artificial nutrition and hydration to people in a state with disorders of consciousness. The position adopted in this thesis urges the need for caution in making a diagnosis of patients in a vegetative state, and allows that a minimally conscious state might develop from an apparently stable vegetative state. However, when there is moral certitude from clinical evidence that the patient is in a vegetative state condition that seems permanent, one is morally justified to say that the medical intervention of ANH is no longer “in principle” a proportionate measure of care (O'Rourke, 2008b, 190).

The question is whether there can be a state that is beyond doubt irreversible with sure indicators to confirm the diagnosis and competent medical professionals available to confirm this state. If so and if there is a certainty that such a way of acting will not cause any pain to the patient, then it would not be unethical to discontinue life-prolonging medical treatment (McCormick, 2006, 370).

The decision to prolong or withheld a treatment ought to take into consideration whether the life to be continued on earth might be too burdensome or not, due to the sufferings and inability of attaining the purposes of life. It may be objected that such considerations can lead to a slippery slope where a steadily increasing number of patients are deemed to have a too burdensome future. However, there are some rather objective criteria to discern whether a future life will be a mere biological life or an embodied spiritual life. It seems that one can determine that a patient is in a stable vegetative state for at least one year; then there is no further recovery to a healthier state possible. When however the patient is in a transitional vegetative state or in a minimally conscious state, then there is an amelioration of health that is possible; however, sometimes the amelioration can be very little and many times it may not occur. These criteria might not



solve all difficult cases, although they do avoid making neither death nor life absolute criteria. When one can establish that the criteria a patient must meet, because one certainly should be able to say that the patient will not be able to regain a social and communicative life again, then there is also an opportunity to say that it might be better to let the patient die. The suggestion resulting from this thesis is that a patient ought to have been stable in a vegetative state for one year, and that the doctors involved agree that it is a vegetative state and nothing else.

## 12.2 A reception disclaimer

The conclusions of the thesis are not contrary to an often admirable defense of human life. This thesis states that a Christian belief in the resurrection is compatible with the idea that all efforts do not always need to be done to awaken unconscious patients.

Some readers might be amazed that the thesis, despite a more open approach to the issue, with its recommendation of a one year observation of a patient in a stable VS, still is far from the daily reality of health care today, where decisions are sometimes made within the same week that a person has become unconscious. The thesis does underline that all reasonable proportionate efforts to respect the value of the human life must be made.

## 12.3 Further considerations

In this section certain difficulties will be taken up that emerged while the master's thesis was written and that deserve further elucidation in future work.

The need for a better understanding of the criteria for the different states of consciousness and of the discernment whether one is dealing with a stable or transient VS has on several occasions been highlighted in this paper. It is essential for the ethical evaluation of a moral case that one knows whether a person is in a stable vegetative state and that there is no hope of recovery or in a minimally conscious state with a tiny hope of recovery.

The autonomy concept needs to be discussed as this today produces the sharpest contradictions concerning medical care at the end of life on a society level. How do patients who are in an unconscious state keep their autonomy respected? In this thesis it

seems that if people are encouraged to designate a person who has the legal responsibility to respect this person's wishes regarding health care issues, this would solve many problems related to how to serve this person in the most appropriate way. Public health attorneys can resolve the question what to do now with an unconscious patient; however, they cannot replace the autonomy of a conscious patient, deciding what type of life the patient would currently prefer. Rahner's distinction between an autonomous death of arbitrary independency and a theonomous death that is accepted with open-minded freedom, would probably be greatly helpful to this further discernment (Linnane, 2005, 165).

This thesis has given the readers greater clarity to the ethical issue of whether ANH ought to be given to persons in a state with DOC, and to the interpretation of recent statements from the magisterium. A clearer and broader horizon brings with itself new questions, and this thesis will hopefully inspire further research.

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