



Some Considerations about Ethical Dilemmas of Artificial Nutrition and Hydration of Patients in a Persistent Vegetative State from the Christian Perspective

Szaniszlo IMV*

Department of Political Philosophy, Pontifical University of St Thomas Aquinas, Italy

*Corresponding author: Inocent Maria V Szaniszlo, Department of Political Philosophy, Pontifical University of St Thomas Aquinas, Largo Angelicum, 100184 Rome, Italy, Tel: +39066702205; Email: szaniszlo@pust.it

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Abstract

Number of so-called apallic patients in the world continues to grow, and this brings not only economic, social but also ethical dilemmas to all who are concerned. This study presents ethical aspects, and arguments for finding appropriate ways to take care of the dying, and in dealing with ethical dilemmas that may occur in palliative care. Such dilemmas concern issues like artificial nutrition and hydration, pain-relief (i.e. the use of opiates), chemotherapy, experimental treatments, ventilation, and the resuscitation of a patient. Here, in particular, we will analyse questions concerning artificial nutrition and hydration (ANH) of patients in a persistent vegetative state (PVS), which constitutes one of the most complex ethical issues in palliative care. We intend to clarify the question, if administration of artificial nutrition and hydration is only a mechanical prolongation of human life and under which circumstance is ethically imperative. After this rapprochement we present a Christian perspective on the duty to preserve a human life. Christian anthropology shows that humans are made in the image of God, which brings people also to their responsibility to care about the lives of others, especially those who are unable to take care of themselves. This responsibility not only rests not upon physicians, but on all of us.

Keywords: Embodiment; End-of-Life Care; Prolonging Life; Human Dignity; Ethical Decisions

Abbreviations: ANH: Artificial Nutrition and Hydration; PVS: Persistent Vegetative State; CVP: Central Venous Line Technique; NG: Nasogastric Tube; ICU: Intensive Care Units; fMRI: Functional Magnetic Resonance Imaging.

Introduction

We live in a time where the prevailing duty of physicians is to prolong and maintain life at all costs, and where death is deemed as a “defeat of life.” At the same time ethicists and physicians increasingly talk about institutionalized dying which means that and the struggle with death is often outsourced to institutions and hospitals. Here, one often dies alone in the presence of life-prolonging technologies, rather

than in the presence of other human beings. On the other hand, we are beginning to talk more and more about taking life and its end in our own hands according to individual needs and wishes.

There are different viewpoints among ethicists and physicians as to whether or not artificial nutrition and hydration is a medical intervention, and whether the denial or the withholding of artificial nutrition and hydration equals the decision to allow a patient to die. Proponents of artificial nutrition and hydration in this context insist that a person in PVS has a right to ordinary medical care. Other bioethicists consider artificial nutrition and hydration to be a medical intervention, and not part of ordinary care. According to the

Catholic Church, to say it short, there should be always an assumption in favour of providing nutrition and hydration to all patients, even if medically assisted, as long as there is a sufficient benefit to the patient, which outweighs the burdens involved [1].

In our middle European countries, many of them with a communist past, adequate care for the dying is complicated not only by financial constraints, but also by considerable efforts from the side of relatives and physicians to maintain human life as long as possible. The reason for the latter is to be seen in the fact that for instance in Slovakia hospices and palliative care units do not have a long tradition and accordingly public knowledge about palliative care is very poor. If we in Slovak universities ask students what palliative care is, only in a few cases they get a correct answer. Generally, in the middle European region, in contrast to for ex. German speaking countries, medical ethics is less accepted in clinical institutions and hospitals because of the very long communist period during which western developments in medical ethics have not been appreciated and received. Physicians consider ethics as something not really necessary.

This paper does not claim to find answers to all of these ethical issues, but rather offers ethical and Christian criteria and solutions to some of them based on selected sources and considerations. Our Christian approach to the problem seeks to answer after more than 40 years of absence of any Christian arguments in the medical ethics of Central Europe. Despite the fact that civil society in the region remained largely Christian even after the period of totalitarianism, it had no formation in this respect. For this reason, we consider the Christian perspective to be an enrichment of the current scientific dialogue of the "Visegrad Region". This is because Christians also have the right to form in the religion to make choices according to their conscience.

What is Patient Vegetative State?

For this reason, let us once more explore what "PVS" or, as it is also known, "post-coma unresponsiveness" is. According to Kenneth Maiese from National Heart, Lung, and Blood Institute in USA, a vegetative state is absence of responsiveness and awareness due to overwhelming dysfunction of the cerebral hemispheres, with sufficient sparing of the diencephalon and brain stem to preserve autonomic and motor reflexes and sleep-wake cycles. Patients may have complex reflexes, including eye movements, yawning, and involuntary movements to noxious stimuli, but show no awareness of self or environment. Compared to that a minimally conscious state, unlike a vegetative state, is characterized by some evidence of awareness of self and/or the environment, and patients tend to improve. Maiese adds that the Diagnosis is clinical and treatment is mainly

supportive. Prognosis for patients with persistent deficits is typically bleak [2].

The syndrome was first described in 1940 by Ernst Kretschmer who called it apallic syndrome. In 1972, Jennett B, Plum F, et al. coined the term PVS to describe a class of patients with unawareness of themselves and their environment but with retained arousal and sleep-wake cycles [3,4]. Pathological studies of patients with PVS who have sustained diffuse hypoxic-ischemic insults have shown diffuse cerebral cortical neuronal damage with sparing of brain-stem structures (Dougherty/Rawlinson/Levy 1981, 991). PVS is a condition in which a person loses the higher cerebral powers of the brain, but maintains sleep-wake cycles with full or partial hypothalamic and brainstem autonomic functions. PVS includes periods of arousal and the return of sleep-and-wake cycles when the patient seems "awake" but unfortunately is never aware. Although they remain unconscious and unaware, PVS patients may appear to be interacting. Moreover, patients in a PVS are incapable of sentience, feeling, or suffering [5].

According to Nelson and Bernat there are the following criteria for the clinical diagnosis of a PVS:

- Patients lie with their eyes open or will open them to stimuli.
- Spontaneous eye movements are present, but there is no sustained visual pursuit.
- There is no ability to follow commands.
- There is no evidence of cognitive response to any stimulus.
- There is no voluntary action or behaviour.
- There is no recognizable language, and patients are usually mute.
- Brain-stem reflexes and sleep-wake cycles are intact.
- Spontaneous breathing is present.
- Double incontinence is presented (Nelson/Bernat [6]; The Multi-society Task Force on PVS).

These criteria for diagnosing a PVS lead to a further point, to "vegetative state recovery." The prognosis for recovery is an essential feature of the moral analysis dealing with patients in a "vegetative state." The prognosis for recovery is to be determined according to Fine, "by the cause of the injury, comorbid conditions, and length of time one has been vegetative:

- a) Duration greater than 1 month is said to be persistent;
- b) Duration greater than 3 months when the cause is non-traumatic, such as anoxic brain injury after CPR is permanent;
- c) Duration greater than 12 months after traumatic brain injury is permanent [7].

In the case of artificial nutrition and hydration, water,

even when administered artificially, cannot be considered a mere medical procedure because without it, the patient will die not because of his/her illness but because of dehydration. Regarding such decisions it is therefore necessary to ask the following question:

- a) Does the provision of nutrition and hydration benefit or burden the patient?
- b) Does the principle of proportionality apply to such ethical dilemmas, similar to cases involving dialysis?
- c) How should one proceed in cases of patients who refuse such ordinary care?
- d) Is the administration of artificial nutrition and hydration only a mechanical prolongation of life?
- e) How should one approach the families of these patients, who often ask for extraordinary care for these patients?
- f) Why do we not let people just die when death is inevitable?

Finally, starting from here, let us present some ethical aspects and arguments for an appropriate care of the dying, and for dealing with ethical dilemmas that may occur in the context of palliative care. When discussions about end of life treatments come up, people will often say something like this: "I don't want to be a burden to anyone. No tubes for me. I just want to go quickly and peacefully." People on the one hand are attracted by technology and what it has to offer them when they are sick, but on the other hand they also have fears about it especially when they are in a weakened or vulnerable state. They imagine becoming trapped in a situation where they aren't allowed to die but are held in a kind of suspended animation by machines. They also worry that their pain may not be managed well. Sometimes they may feel pressure from family members that they shouldn't "stick around" too long [8]. These kinds of fears and concerns however need to be scrutinized carefully, because they can prompt us to act rashly and think unclearly when it comes to making concrete treatment decisions. In addition, the patient consent institute is not yet sufficiently widespread and understood in the Central European context. Often, this process narrows only to "some signature" of the document by the patient, which protects the doctor rather than helping the patient.

If we speak about ethical dilemmas, we can note that an on-going debate during the last 10 years exists as to how much care, if any, patients in a PVS should receive in health systems plagued by limited resources. For example, in a case before the New Jersey Superior Court, *Betancourt V Trinitas Hospital*, a community hospital sought a ruling that dialysis and CPR for such a patient constitutes futile care. The patient died naturally prior to a decision in the case, resulting in the court finding the issue moot [9]. And an American bioethicist, Jacob M Appel, adds a proposition that any money spent treating PVS patients would be better spent on other patients

with a higher likelihood of recovery [10].

End-of-life care is a complex and difficult task for PVS patients and their families as well as for health care professionals who provide them with daily care and treatment. It is our duty in end-of-life care to provide loving and qualified care for PVS patients, and also to provide them with all possible treatment and to help them understand their suffering and dying. Only in the United States, it has been estimated that there are between 15,000 and 40,000 patients in a PVS, but since home nursing records are kept inaccurately, the exact number is difficult to determine. Up to 70% of coma patients are cared for at home in the family. This seems all the more desirable since the border to the minimally conscious state cannot be drawn with absolute certainty and emotional reactions are most likely to be expected. With appropriate professional support (outpatient care services), this can often be done physically and psychologically for the families [11].

Nutrition and Hydration in End-of-Life Situations and PVS

The most common ethical dilemmas in end-of-life care are concerned with issues like artificial nutrition and hydration, pain-relief (i.e. the use of opiates), chemotherapy, experimental treatments, ventilation, and the resuscitation of a patient. Among these we will concentrate on artificial nutrition and hydration (ANH), a new medical technology which can provide sustenance to persons who are unable or unwilling to ingest food or drink, in end-of-life situations. First we will give an overview over ANS as a medical treatment-possibility in three parts:

1. Concerns regarding the feeding of PVS patients.
2. Technical provision and medical benefits of ANH and.
3. Clinical factors which can limit the provision of ANH.

First, let us address some concerns regarding the artificial feeding of PVS patients. According to Carson, "the very act of giving drink and food carries within it a profound symbolic meaning which speaks directly to those involved. This symbolic meaning, though elusive, reveals the importance of providing another with the essentials of life" (p. 85) [12]. Especially in the case of PVS patients it is of great importance to take into consideration this symbolic meaning. Feeding PVS patients has to be seen as an expression of "human solidarity" (p. 1) [1]. As ANH for PVS patients continues to be a point of contention among ethicists and theologians, one issue seems to be very clear to us: the symbolic meaning of the provision of food and water may be of high significance, but cannot in itself sufficiently determine the rightness or wrongness of such actions.

Another concern regarding artificial feeding of PVS

patients and related to its symbolic meaning, is that the provision of ANH to PVS patients is accompanied by many emotions for both the patient and his family. Hence it is necessary for the medical staff to be very attentive to the patient's responses, to his family, to the age and general health of the patient and to the definite diagnosis including the definite prognosis of an early death (p. 1) [1]. Any negative or non-professional reactions may cause numerous stress responses or subsequently generate ethical and legal problems.

Secondly, the technical means of ANH have been developed over many years. Specifically, modern intravenous methods have replaced older procedures. A major advance in the 1960s was the introduction of the *central venous line technique* [CVP] [13]. Today, "ANH is administered entirely (*via the gut*) through a nasogastric tube [NG] or a gastrostomy [PEG] or jejunostomy tube that is placed with fluoroscopic or endoscopic guidance" (p. 226) [14]. Generally this method causes no complication. ANH may also be administered parentally (*via any route other than the gut*) through peripheral or central venous access¹. Hydration alone can also be provided by subcutaneous infusion.

ANH may improve survival among patients who are in a PVS. These patients may live for 10 years or more with ANH, but will die within weeks without nutritional support [15]. ANH may improve the survival of patients in the acute phase of a stroke or head injury and among patients receiving short-term critical care [16]. It may also improve the nutritional status of patients with advanced cancer who are undergoing intensive radiation therapy. Nowadays, nutrition and hydration are generally available and can be pretty well adjusted and prepared according to the needs of the individual patient. Problems often arise when terminal patients from intensive care units (ICU) are transferred to other units. If there is a gradual decline in the function of the patient's organs medical authorities often continue to administer artificial nutrition as prescribed in the ICU. In such cases, nutrition could sometimes be reduced at the cost of the energetic and nutritional needs of patients, as it is suggested in some manuals of intensive medicine in Slovakia. Literature on palliative care in terminal stages recommends reduced ANH at the cost of non-compliance with energetic and nutritional requirements [17].

Third, the provision of ANH can be associated with considerable medical risks. For instance, patients with

¹Nasogastric tubes are inserted and placed through the nose, down the oesophagus and into the stomach and do not need surgery; gastrostomy tubes are inserted through the abdomen into the stomach by means of surgical incision; jejunostomy tubes are inserted surgically through the abdomen directly into the small intestine; nasojejunal tubes are inserted gastroscopically through the nose to the jejunum and do not require incision through a stomach (Pastekova, 2014). Total parenteral nutrition is infused into a large vein (Flynn 1990, 2).

advanced dementia who receive ANH through a gastrostomy tube likely have to be physically restrained and are at an increased risk of aspiration pneumonia, diarrhoea, gastrointestinal discomfort, and problems associated with feeding-tube removal by the patient [18]. In addition, when a patient's vital functions decline at the end of life, ANH may cause choking due to increased oral and pulmonary secretions, dyspnoea due to pulmonary oedema, and abdominal discomfort due to ascites [19].

The vegetative state must be distinguished both clinically and juridically from the conditions defined as brain death or irreversible coma. In these cases there is the complete and irreversible loss of brain activity, confirmed by electrophysiological recordings, and related vital functions, including respiratory activity. Brain death is, therefore, a completely different condition from the vegetative state, which is not recognized as death in any legal system. However, there remains a legal "grey area" around this state. This fact led to some media and legal controversies concerning people in a state of alert coma, with heated bioethical debates. If we do not accept the substitution of disability for lack of consciousness then the evidence is indisputable that PVS is not necessarily permanent and not unquestionably insentient.

In such cases, physicians often seek to speak to the relatives in order to agree on basic care for PVS patients without life-supporting measures and to make it easier for the patient to say goodbye, taking into account the guidelines on euthanasia. In particular, the prospect of a non-self-determined life in the Apallic Syndrome repeatedly sparked discussions among German medical associations and politicians regarding active euthanasia. This was still punishable under German law due to the atrocities of the Third Reich till 26th February 2020 until the German Constitutional Court has brought the other decision [20]. The care of PVS patients is also associated with considerable psychological stress for the nursing staff. Because the time-consuming care of the imperceptible patient is often perceived as extremely frustrating [21].

Known cases include Paul Brophy, Sunny von Bülow and Tony Bland, who set a precedent in the UK. The highly publicized case of Terri Schiavo in the United States involving disputes on diagnosis of PVS issued by various physicians appointed by the court. The appeals brought to the court were rejected and Terry Schiavo's nasogastric feeding tube was removed, leading to death. The Italian case of Eluana Englaro is analogous.

On the other hand, in 2010, British and Belgian researchers reported in an article in the *New England Journal of Medicine* that some patients in persistent vegetative

states actually had enough consciousness to “answer” yes or no questions on fMRI (Functional magnetic resonance imaging) scans. However, it is unclear whether the fact that portions of the patients’ brains light up on fMRI will help these patients assume their own medical decision making (possible change of patient’s informed consent). The same bioethicist Appel told the Telegraph that this development could be a welcome step toward clarifying the wishes of such patients. Appel stated: “I see no reason why, if we are truly convinced such patients are communicating, society should not honour their wishes. In fact, as a physician, I think a compelling case can be made that doctors have an ethical obligation to assist such patients by removing treatment. I suspect that, if such individuals are indeed trapped in their bodies, they may be living in great torment and will request to have their care terminated or even active euthanasia” (Alleyne & Beckford 2010 4th Feb.). Personally, we think that in such communication we can also see the opposite surprise. Decision about termination of his own life, because in our opinion, is not a natural form of human behaviour, in spite of suffering that even in modern times may be less unbearable, because patients may not actually be required.

The Duty to Preserve Human Life from a Christian Perspective

Human life is a gift we should respond to with gratitude, awe and reverence. This belief in life as a Creator’s gift enables them to maintain the sanctity of life. From a Christian point of view humans are made in the image of God. This brings people not just to our Creator, but also to their responsibility to care about the life of others, especially those who are unable to take care of themselves, or are afflicted by specific medical conditions like a PVS and are in need of somebody’s help. It is essential to remember that this responsibility rests not just upon physicians, medical personnel or somebody else alone: It rests upon all people.

With regard to PVS and to the question of ANH, we have to be very careful and wary of personal or familial selfishness, of societal pressures, and even more importantly of premature medical prognoses. As we just said, the list of these cases and corresponding discussions is very long (from Tony Bland through Terri Schiavo till Otto Warmbier). After witnessing in another type of the case, this of Tony Nicklinson, a patient with locked-in syndrome, who wanted to end his suffering by taking lethal doses of a drug, which is not legal in the UK, the former Archbishop of Canterbury George Carey, who had opposed assisted suicide in the past, said that his “old philosophic certainties collapsed in the face of the reality of needless suffering.” Asked to make a comment on this, Charles Scicluna, then Archbishop of Malta, said he believed that “many claim that the movement to embrace assisted suicide as a public policy is led, not by suffering patients, but

by the ‘worried well’; those who are terrified of the loss of control that illness and death bring about” [22].

In this context, principles like those already presented by Pope Pius XII, specifically his explanation of ordinary-extraordinary means, could allow us to be committed to the sanctity of life as well as to be attentive to the quality of life of the individual person or patient. Essential to this approach is a prudent judgment which gauges the proportion of benefits and burdens of a particular means of conserving life. A veritable Christian obligation to help those patients is present, as Scicluna adds in the above mentioned interview, only insofar as the provided treatment is beneficial. Every human life is valuable, but this does not mean that every human life must be sustained indefinitely [22].

However, the use of the diagnosis of PVS does contribute to the institutionalization of life and death authority in the medical profession. Some ethicists believe, like Dworkin, that it is in the best interests of people with such severe disabilities to have “the right to die” invoked on their behalf. We would all be happier if we could be sure that people in unendurable situations were unaware [23]. With this right to self-determination, human autonomy is taken to a qualitatively new level. From a legal point of view, one of the laws governing these patients is the law on the rights of patients and the end of life, known for ex. in France as the Leonetti law (and recently in Germany), which aims in particular to avoid relentless therapy for people who would have, for example, previously made arrangements, while they were in good health, for the type of care they would like or not want, if they should find themselves in this situation, in particular by an advance directive. We must say, however, that the basic rule of the Judeo-Christian culture, which forbids killing a person in the application of this new (especially German) legislation, which gives physicians and others persons the opportunity to submit a lethal means, runs into a very contradictory logic of interpretation of fundamental rights. If the physician whose profession is to treat people is to be the messenger of the end of a patient’s life, the whole theory of human rights is threatened. In essence, it seems as if the endeavour of the secular society at the end of the 20th century to culminate in the right to self-determination of a person without relation to the founder and defender of these rights. It will be interesting to sit down the reaction of a post-secular society, which has been starting to speak (even violently) of the word since the beginning of the 21st century. As ethics we know that every action instigates a reaction. Finally, on this controversial topic, we can only add Böckenförde statement that: “The liberal, secularized state lives from conditions that it cannot guarantee itself”².

² First in 1967, in the essay *The Formation of the State as a Process of Secularization*, Böckenförde had shown how the political order in modern history of secularization “frees itself from a given religious-political world

Thus we see that the Christian perspective is aware that on the one hand, every life deserves to be protected, but on the other hand, the limits of the protection given the importance of a final decision by the physicians, patients and families in the absence of positive developments in PVS patients. However, even in such cases, the solution, according to the Pontifical Academy for Life, is not active euthanasia, but just palliative care as it said Pope Francis: «Palliative care accomplishes something equally important: it values the person. I exhort all those who, in various ways, are involved in the field of palliative care, to practice this task keeping the spirit of service intact and remembering that all medical knowledge is truly science, in its noblest significance, only if used as aid in view of the good of man, a good which is never accomplished “against” the life and dignity of man» [24].

Some Final Considerations

First of all, it seems that our society has made the difference between people who die because they are ingested in food and water, and people who forget to ingest in food and water due to the natural dying process.

Second, every patient, including one in a vegetative state, has the right to basic medical care.

We agree with Pastekova, that due to the technical excellence of cardiac supports we finally think that in the near future, the issue of end-of-life care will move from the administration of food and fluids to push for a possibly earlier shutdown of the technical devices [17]. Man must have a possibility, if his life goes naturally to death, to die, and we are strongly for this solution.

Mons Scicluna repeats that only treatment that offers a reasonable hope of benefit is morally acceptable. Why? Because life has a fundamental value, not an absolute value.

Finally, the end-of-life decision, which is always very difficult, also depends on the collaboration of doctors, nursing staff and other relevant professionals such as psychologists, theologians and ethicists.

In conclusion, we hope that all of these ideas based on our research from a Catholic Christian perspective will only demonstrate our shared concern and love for these critically ill patients. They attest to the genuine and unselfish nature

of unity” and formulated the result as follows: “The liberal, secularized state lives from conditions that it cannot guarantee itself.” When asked what that meant, Böckenförde replied to the daily newspaper in 2009 that the state had to rely on “citizens have certain basic attitudes and a state-supporting ethos” because otherwise it would be difficult “to implement a policy that is oriented towards the common good”. Bockenforde protested against a purely religious misunderstanding of this ethos: Society needs a basic consensus on common ideas in order to act in solidarity (von Thadden 2019).

of Christian love that are expressed, even if those who receive it continue to show no appreciation - even if they are apparently not aware of this loving presence at all. For in the care only for those who can thank us and do we not already return the reward?

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