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# Permanently Unconscious Patients and The Ethical Controversies Surrounding Artificial Nutrition and Hydration: Getting the Facts Straight

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## INTRODUCTION

### Current Debate

The provision or otherwise of artificial nutrition and hydration (AHN) is, and has been for some years now, a matter of great controversy. The issue of ANH is made more complex when the patient is incompetent, that is to say, incapable of ever making a free and informed choice as to its provision or otherwise. The permanently unconscious patient, and in particular, the persistent vegetative state patient (PVS) and the comatose patient are two examples of incompetent patients for whom the resolution of this very complex issue has important life and death consequences.

We believe that movement towards an early ethical resolution of the ANH controversy is unlikely, at least in the case of the permanently unconscious patient, for a number of reasons. First, existing confusion engendered by differing interpretations of what constitutes effective treatment and whether in fact ANH itself is a medical treatment, or, simply part of the ordinary nursing care owed to all patients unconscious or not. Second, there are the ambiguous meanings and time limits of commonly used terms such as *imminent death*, *terminal condition* and *dying*. Third, the number of different terms used to describe the medical status of the permanently unconscious, for example, *persistent vegetative state*, *coma*, *comatose*,

*irreversibly comatose, chronically comatose*, to name but a few. Fourth, there is the failure by many involved in the ANH debate to grasp all of the medical facts concerned with the reality of the permanently unconscious patient. Fifth, this failure to clarify the medical facts has led to arguments favoring the withdrawal of ANH that are inconsistent with both the Doctrine of Ordinary and Extraordinary means, on the one hand, and prevailing clinical practice, on the other. Sixth, there is our unwillingness to seriously debate the principle of "justice as fairness" in the context of the permanently unconscious and their persistent drain on the scarce health resources. Finally, deficiencies in our knowledge regarding the neuropsychophysiology of the brain hinder our understanding of the nature of the life that remains.

It is now 15 years since Karen Ann Quinlan (a PVS patient) occupied the collective ethico-legal minds of the Western World. Yet it is clear from accumulated writings that we are still puzzled and confused, not only about what PVS is, but also about the status we should accord such a patient. Is the PVS patient dying, terminally ill, a person, sub-person, non-person, or even dead? We are still engaged in a sometimes bitter debate about what principles should govern treatment decisions for these patients. Indeed some, maybe many, worry about whether these patients should be considered alive at all.<sup>1</sup> If PVS patients be indeed alive, why the relentless use of artificial nourishment and other treatments to perpetuate unconscious existence? Can this be an extraordinary use of extraordinary means, heroic in the extreme and ultimately useless, or, at best, marginally beneficial in that it seems to offer no net benefit for the irreversibly unconscious?<sup>2</sup>

Should the cost of continued health care for the permanently unconscious be a factor in clinical ethical decision-making? While costs vary, it is undeniable that it is a costly exercise to maintain these patients in a *persistent* vegetative state. Grisez argued, for example, that an affluent society should feel obliged to meet the costs, whereas an impoverished community must first ensure a just allocation of its scarce health resources.<sup>3</sup> Can this argument be sustained in the face of the 5,000 to 10,000 PVS patients in 1988 in the USA alone, a figure that was predicted to significantly increase in the future, especially when coupled with the increased longevity of people?<sup>4</sup>

Because the PVS patient can survive for decades, when life supports are withdrawn, the causation of death, assuming the PVS patient is indeed alive, may seem to be the act of withdrawal itself and not be because of any significant impact of the condition itself. This problem is all the more vexing because the usual treatment issue in the case of a PVS patient is whether to stop artificial nutrition and hydration, still the most controversial form of treatment withdrawal. PVS tests the traditional boundary between the withdrawal of life-sustaining treatment and active euthanasia; withdrawing treatment from PVS patients may appear to be active killing.

While it is widely accepted that life-sustaining treatment may be withdrawn when the burdens to the patient truly outweigh the benefits, PVS patients push our commitment to this patient-centered standard to the limit. It is said that the PVS patient experiences nothing: the benefits and burdens of continued treatment fall

mainly on others. They tether their families to the hospital bed, to keep silent vigils for many years and often decades. In deliberately prolonging the lives of PVS patients, are we in effect ourselves causing the *persistent* vegetative state? In facing the future, if not the present reality of thousands upon thousands of PVS and other permanently unconscious patients, existing as bundles of humanity huddled in automated feeding wards, will they be there because of our ethical commitment to their humanity, or, because of a creeping ethical paralysis in the face of biotechnical progress?

In this paper, we intend to examine several of the major controversies which bear on the issue of providing or withdrawing ANH to the permanently unconscious, and, in particular, the PVS and comatose patients. We intend also to take up the medical status and nature of PVS as did Smith, who argued that the PVS patient, though unconscious, was not dead and, therefore, still retained the status of person.<sup>5</sup> However, we will focus on the implication that he himself identified: "*The moral issue is not whether PVS patients can be kept alive but whether there is a moral obligation to do so.*"<sup>6</sup> In so doing, we will examine a number of contentious issues mentioned earlier, issues including the status of ANH as a treatment, whether it is a burden or benefit, the ambiguous use of terminology and the notion of "fatal pathology".<sup>7</sup> We will also re-examine, from a different perspective, Grisez's arguments in support of ANH for the comatose patient in the context of their specific medical reality vis-a-vis that of the PVS patient.<sup>8</sup>

We intend to argue, that, whereas the withdrawal of ANH from most PVS patients is unjustified, the withdrawal of ANH from some comatose patients may well be justified. By way of background, a brief review of some recent legal cases and statements by the American Medical Association (AMA) involving ANH will help frame the ethical debate.

## Recent History

Opinion in recent years has favored the view that health professionals are not necessarily obliged to provide medical treatments that are seen as futile and, where the burdens to the patients outweigh the benefits, such treatments are said to be morally optional in the case of the terminally ill patient. It was presumed, however, that the decision in the *Quinlan*<sup>9</sup> and *Saikewicz*<sup>10</sup> cases ensured that ordinary forms of patient support, such as nutrition and hydration, would always be provided. That presumption was seriously tested and eroded by *Barber vs. Superior Court*,<sup>11</sup> where the doctors of Clarence Herbert withdrew intravenous nutrition and hydration. The Supreme Court determined that the burdens and benefits of care must be evaluated and, where the burdens were disproportionate to the benefits, a doctor was not obliged to treat. They further determined that the provision of artificial nutrition and hydration was similar to other medical treatments and could, therefore, be optional and terminated when its provision would be ineffective.

Meanwhile, in 1982, the American Medical Association's Council on Ethical and Judicial Affairs stated that in cases of well-confirmed *irreversible coma*, even where death was not imminent, "*all means of life support may be discontinued.*"<sup>12</sup> A year later, in 1983, the President's Commission For the Study of Ethical Problems

in Medicine, in its report on the termination of life-sustaining medical treatment, maintained that no medical intervention, including a feeding procedure, is required if it merely delays the moment of death.<sup>13</sup> The Commission's Report recommended that no distinction be drawn between tube feeding and other forms of life-sustaining treatment, such as dialysis or ventilation. In the case of permanently unconscious patients such as Barber, the Commission held that the sole conceivable benefit is sustaining the body, which it viewed as no real benefit at all. Not only can the costs be burdensome to the family and society, but a policy of providing nutrition and hydration may well violate the autonomy of the patient. The Report further recommended, as reported by Horan, "that the essential conclusions of the California appellate court be adopted in other legal jurisdictions."<sup>14</sup>

The Barber case was quickly followed by a series of legal cases which included *Brophy*,<sup>15</sup> *Jobes*,<sup>16</sup> *Corbett*<sup>17</sup> and *Gray*.<sup>18</sup> Marcia Gray, like Clarence Herbert, was described as being in a *coma*, whereas Brophy, Jobes and Corbett, like Karen Quinlan, were described as being in a *persistent vegetative state*. The more recent case of *Nancy Cruzan*<sup>19</sup> who, like Karen Quinlan before her, is a young woman who has been in a persistent vegetative state since 1983. Despite her parents' belief that she would not want to continue to live in a permanent unconscious state, the court has refused their request to have a gastrostomy tube removed from their daughter. Commentaries on these legal cases can be found in papers published in the *Linacre Quarterly* by Horan<sup>20</sup> and Helsper and McCarthy.<sup>21</sup> Then, in 1986, the Council of the American Medical Association clarified its 1982 statement by specific reference to nutrition and hydration, holding that "life-prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration."<sup>22</sup>

Most professional organizations and commentators have resisted radical statements on the issue of ANH and have limited their pronouncements and opinions to those *terminally ill* patients whose death is *imminent* and to those patients who are *permanently unconscious*. However, other commentators have argued not only for the withdrawal of nutrition and hydration from *comatose* or *irreversibly comatose* patients, but also from those who are seriously but not terminally ill. Understandably, many clinicians, lawyers, bioethicists and others remain confused or puzzled not only by the number of terms used to describe the medical status of the unconscious patient, but also by the meaning of *dying* and the limits of the terms *terminal* and *imminent*.<sup>23</sup>

## Artificial Nutrition and Hydration

### Defining Treatment

The controversy central to existing confusion revolves around the medical status of ANH. Is ANH a medical treatment in the same sense as respirators, medication and surgery? If yes, and depending on the circumstances, ANH can be construed as optional or obligatory in the same way that other medical and surgical procedures are sometimes construed as optional. This was the position taken by the Higher Appeals courts as seen in *Barber* and the final decision in *Conroy*. However, in the lower court's responses to *Conroy* and *Brophy*, it was ruled that ANH was not

equivalent to medical treatment. The distinction is crucial, because if ANH is considered a part of *ordinary routine care*, then the obligation to provide that ordinary care is more stringent than to provide that which is considered a *treatment* and which, given a poor prognosis for the patient, may sometimes be seen as *extraordinary* and therefore morally optional.

McMillan saw the issue as pressing because technology has made it possible to keep people alive on feeding systems for indefinite periods of time. The *moral line*, as McMillan<sup>24</sup> puts it, between medical intervention for therapeutic ends and ordinary hygienic care, cannot now be easily drawn. Sometimes the provision of nutrition and hydration looks like ordinary care, at other times like treatment which is futile and, in still other cases, it looks like both at once — a gesture of ordinary care (and therefore required), but perhaps futile, and if so, unjustified.

Griese, though he argued that feeding remains a part of ordinary care even if administered by artificial means, admitted that the artificial feeding process can constitute recourse to an extraordinary means in particular cases if it is useless or excessively *burdensome*.<sup>25</sup> Lussier was, however, prepared to concede ANH as a form of treatment, whilst arguing that it is not, however, equivalent to other forms of medical treatment.<sup>26</sup> According to her, there exists a continuum of treatments varying in both degree of invasiveness and *moral requiredness*. Antibiotics and ANH are at one end of the continuum and high invasive treatments such as cardiac surgery are at the other.<sup>27</sup> "They should not be lumped together," claims Lussier, "so that a decision about one form of therapy is found automatically to apply to the others."<sup>28</sup> For example, Lussier claims that since ANH is generally non-invasive, ". . . basic and benign, much stronger mitigating circumstances would be required to justify its discontinuance."<sup>29</sup> In cases where the provision of ANH causes problems (eg. sepsis), it would not be benign and would be less required. Lussier seems to be arguing the case for ANH to be sometimes perceived as *ordinary means* and therefore morally obligatory to provide while, at other times, to be perceived as "*extraordinary means*" and, thereby, making its provision morally optional, in which case decisions regarding its provision, or otherwise, are essentially no different from those interventions about which there is no controversy.

Smith, on the other hand, argues that, within ordinary means, there is a subset of means that should be defined as minimal. "Minimal means," he claims, "are always presumed to be 'ordinary' while allowing that their mechanical delivery, in unusual circumstances might, by exception, qualify as 'extraordinary' means."<sup>30</sup> These minimal means would include basic hygiene and supportive measures such as food, water, bed rest and personal hygiene. Mullooly also makes use of the term *minimal means* and in distinguishing between the normal and artificial reception of nutrition and hydration, argues that, when nutrition can be received normally, it must always be provided. However, in providing for the reception of artificial nutrition and hydration, it is possible that the burden of costs may make this form of reception extraordinary and therefore optional for the patient and family.<sup>31</sup>

There seems to be general agreement that the provision of nutrition and hydration should be regarded as just another medical treatment when provided artificially and should, therefore, be open to critical appraisal in terms of whether it is an ordinary or extraordinary means in particular circumstances. There is also a

growing consensus that nutrition and hydration, even when provided artificially, remain a part of *ordinary care*, until or unless, in particular cases, it is clear that artificial provision constitutes recourse to an extraordinary means (useless, futile, excessively burdensome, etc.) in which case, its provision is morally optional.

Miles introduced an interesting perspective into the debate on ANH and whether it should be viewed as a medical treatment.<sup>32</sup> He made the point that “. . . we must keep in mind that the public discussion of the elective provision or withholding of nourishment is heard by two audiences: public policy and private hearts. In public policy, this debate addresses the concerns of institutions and professional groups. This is a debate about the public conduct of institutions. When dying occurs at home, sips of broth lovingly tendered by family caregivers to the limit of satiety fulfill the moral obligations to feed and care. Today, when 80 percent of deaths are in institutions, the recognised physiological inadequacy of these same sips of broth provoke a moral crisis about the conduct of public life. Can food for the vulnerable and voiceless who are dependent on our institutions be elective?”<sup>33</sup>

### Nourishment and Alimentation

The artificial provision of nutrition and hydration, Miles argued, is not the same as normal feeding and does not have the same symbolic or psychological significance to either the patient or the patient's care givers. For example, nourishment as *alimentation* is a medical procedure intended to achieve physiological objectives and is accompanied by medical monitoring to assess its effects. As a physiological intervention, alimentation can be comfortably identified as a medical treatment or intervention. “It belongs,” as Miles argues, “to the ethics of elective medical treatments.”<sup>34</sup> As such, it is subject to ethical reflection as to whether it is, for example, ordinary and, therefore, obligatory, or, extraordinary and, thus, morally optional.

### Nourishment and Feeding

Nourishment may also be *feeding* and, as such, is a broader, non-medical “*caregiving*” social experience. The orientation of both patient and caregiver is towards social interactivity, making the ethic of feeding quite unlike the ethic of medical treatments. Miles further argues that modernised nourishment technology has advanced to the stage where it is now necessary to exercise discretion in its use. In the words of Miles, “We need a different, non-physiologic medical ethic to fully address the problem of feeding.”<sup>35</sup>

Grisez, in summing up the arguments for and against ANH as a form of medical treatment, concluded that both sides erred either because they focused on “feeding” *per se*, or, because they saw the value of feeding as *socially expressive* or *symbolic*. For Grisez, “the real issue is not whether to feed comatose persons or not, but whether to care for them or to abandon them; and that faithfully caring for comatose persons benefits them not only by sustaining their lives but by maintaining a moral bond, which is far more than mere experience and feelings, of human solidarity with them.”<sup>36</sup>

## Dying, Imminent Death and Terminal Condition

Another source of confusion concerns the meanings assigned to the terms *dying*, *imminent death* and *terminal condition*. Variations in their definitions can lead to divergent decisions and patient outcome. Doctors and others seem to use the terms *imminent death* and *terminal condition*, to imply that they can predict that a patient will die of a fatal pathology within a few days or weeks despite the fact that life prolonging methods are already being used. Boyle, King and O'Rourke make the point that using these terms as significant factors in making ethico-legal decisions for seriously ill patients begs the question. "The important issue," they claim, "is not how the patient might live with life support systems, but whether a life support system should be initiated in the first place, or once initiated, for what reasons it may be withdrawn."<sup>37</sup>

Other commentators have examined the meaning of the terms themselves. Lussier argued that the term *dying* can vary on at least two levels.<sup>38</sup> The first level of definition incorporates the phrase *terminal condition* and is, or may be, used to describe patients who, in the absence of life-sustaining technology, would be dying. This might refer, for example, to ANH in the case of PVS and dialysis in the case of end-stage renal failure. In the former case, that of PVS, it is the underlying medical condition, through its effect, it is claimed, on the patient's ability to eat normally that is most likely to cause the death of the patient — this is Boyle's and O'Rourke's notion of *fatal pathology*. The artificial provision of nutrition and hydration prolongs life by delaying what would be a normal dying process.

The definition of dying can also vary in terms of the time the patient is expected to live before dying. *Imminent death* is perhaps the most common and misleading term used to define dying, because, whereas the Oxford Dictionary, for example, defines imminent as "soon to happen", some commentators<sup>39</sup> and Courts of Law<sup>40</sup> have taken this to mean that death is expected within a year. Other commentators argue that something closer to one month would be a more appropriate interpretation of *imminent*. The time frame used to define imminent has important consequences for what happens to the patient. Once a patient is determined to be *dying*, with death *imminent*, there is arguably a decreased or less stringent moral obligation to provide or continue aggressive treatment. It has been well argued by Lussier that the extended time frame of up to one year may well include patients who, at the present time, are, in fact, in a robust condition. To withhold or withdraw ANH from such robust patients would seem morally inappropriate. To avoid the confusion which has arisen over the different time frames assigned to the term *imminent death*, it has been suggested that the term should involve some indication of physical debilitation.<sup>41</sup>

Boyle, King and O'Rourke's comments on *fatal pathology*, in the context of PVS are pertinent to physical debilitation as a sign of imminent death. They argue that, because a person in a PVS cannot chew or swallow, they have a fatal pathology and will die in a short time, unless life-prolonging procedures are used to compensate for the pathology. Withholding ANH from such a patient in this debilitated condition does not induce a new fatal pathology. Rather, it allows an already existing fatal pathology to take its natural course. They claim: "Hence, when making ethical



or legal decisions concerning the care of persons in irreversible coma . . . rather than discussing whether death is imminent, or whether the patient is terminally ill, we should ask whether a fatal pathology is present."<sup>42</sup> The point of their argument is that if a fatal pathology is present, "the significant ethical question is not whether death is imminent, but rather whether there is a moral obligation to seek to remove the fatal pathology or at least circumvent its effects."<sup>43</sup> Unfortunately, whereas the notion of *fatal pathology* lends some clarity to certain ethico-legal questions regarding the status of the comatose patient, it does not necessarily encompass the issue of moral duty. Grisez observes that, ". . . this argument only shows that the decision not to feed a comatose person need not be a choice to kill him or her. It by no means shows that those who can feed the comatose have no moral obligation to do so."<sup>44</sup> In any case, the legitimacy of the claim that PVS patients cannot swallow and, therefore, have a fatal pathology is strongly challenged by the facts of the condition. Diamond, in his commentary on the AMA's statement on tube feedings, had this to say about "fatal pathology": "If the patient were suffering from a fatal pathology, feeding him or her would allow the underlying fatal process to run its course and end his or her life. In the usual type of persistent vegetative state, such an underlying pathology does not characteristically exist. Withholding food and nutrition over time, on the other hand, will have uniformly fatal results."<sup>45</sup>

The first step, when confronted by an ethical dilemma, is to collect and understand the facts, particularly, the medical reality of the patient's condition. In the case of the PVS and the comatose patient the pertinent medical facts were initially presented in some detail by Cranford<sup>46</sup> and represented more recently by Smith.<sup>47</sup> In the present paper, we will summarize only those medical facts relevant to our discussion.

### The Permanently Unconscious

The simplest way of understanding the difference between the PVS patient and the comatose patient, on the one hand, and whole brain death on the other, is to consider the roles played by the brainstem and the cerebral cortex as part of the central nervous system. The brainstem is the stemlike portion of the brain connecting the cerebral hemispheres with the spinal cord and which controls *vegetative* functions such as respiration, the cough, gag and swallow reflexes, and so on. Additionally, it contains the activating or arousal system for the entire upper brain, called the *ascending reticular activating system* (ARAS). The upper brain or cerebral hemispheres, in turn, contain the function of consciousness or awareness, which is more precisely located in the outer layers of the cerebral hemispheres and is called the cerebral cortex.

### The Persistent Vegetative State

When whole brain death occurs, the high cerebral functions cease as do all brainstem functions and the patient is declared dead.<sup>48</sup> By contrast, the brainstem in the PVS condition, including the ARAS, is relatively intact, however, the cerebral hemispheres suffer irreversible damage. Thus, within a short period following the initial trauma, the patient will begin to breathe spontaneously, the eyes will open

and "wander" and respond normally to light, and periods of sleep will occur. The protective gag, cough and swallow reflexes are usually normal and hand feeding is possible by placing food at the back of the throat, thus activating the involuntary swallow reflex. Nonetheless, this is immensely time-consuming and cost prohibitive. All voluntary reactions or behavioral responses reflecting consciousness, volition or emotion at the cerebral cortical level are absent. PVS patients, then, are awake but *amented*, that is, they manifest a complete loss of mental functions. They remain permanently unaware, and may survive for many years, even decades.<sup>49</sup>

### **The Comatose Patient**

In the case of the comatose patient, extensive damage has occurred to the brainstem and the ARAS, thus, they remain sleeplike (eyes closed) and incapable of being aroused. The cough, gag and swallow reflexes are most often absent and ANH is necessary, unlike the PVS patient where it is unnecessary, though convenient. The absence of these reflexes makes them extremely vulnerable to serious respiratory infections, which, in fact, comprises a common cause of death. Thus, in an important sense, as Cranford notes, "it is reasonable to describe comatose patients as 'terminally ill' with death anticipated in six months to a year, unless extremely vigorous therapeutic efforts are made to sustain life."<sup>50</sup>

### **Permanent Unconsciousness**

If PVS patients are unconscious, but not comatose, as many mistakenly believe, what is their medical status? The President's Commission For the Study of Ethical Problems in Medicine clarified the medical status of both PVS and comatose patients, referring to their condition as *permanent unconsciousness*, — the former "eyes open" and the latter "eyes closed" — because there are no cerebral cortical functions on clinical examination suggestive of consciousness.

### **Pain and Suffering**

The American Academy of Neurology unequivocally stated in 1986 in evidence before the Paul Brophy case, that "pain and suffering are attributes of consciousness and PVS patients like Brophy do not experience them. Noxious stimuli may activate peripherally located nerves, but only a brain with the capacity of consciousness can translate that neural activity into an experience."<sup>52</sup> Their evidence rested on the fact that the integrated functioning of the brainstem and cerebral cortex is necessary for the conscious experience of pain. Facial movements and other signs suggesting conscious human suffering are not uncommon, but as Cranford explains, ". . . these actions result from subcortical (structures deep in the cerebral hemispheres that may be relatively undamaged) and brainstem actions of a primitive stereotyped, reflexive nature. In other words, PVS patients may 'react' to painful and noxious stimuli, but they do not 'feel' (experience) pain in the sense of conscious discomfort of the kind that physicians would be obliged to treat and of the type that would seriously disturb the family."<sup>53</sup> With these few medical facts in mind, we can now turn to an ethical analysis of the moral issue raised by Smith. Is there a moral obligation to keep alive the permanently unconscious patient?

## Overriding the Obligation to Provide ANH

### Patient Dead

"Treatment is not obligatory when it offers no prospect of benefit to the patient because it is pointless," so claimed Beauchamp and Childress when arguing that certain conditions justify overriding the *prima facie* obligation to treat — in this case, the provision of ANH.<sup>54</sup>

If a patient is dead, it is argued, the provision of ANH is futile and its withdrawal, together with that of other medical treatments, does not violate the best interests of the patient. Does this condition for overriding the *prima facie* obligation to treat apply to permanently unconscious patients? It is clear that both the PVS and the comatose patient fail to meet the commonly accepted criteria for whole brain death. The former has no cortical functioning, but the brainstem is still functional, whereas, in the latter, the unarousability is due to extensive damage to the ascending reticular activating system of the brainstem. In neither case can the patient be assessed as dead.

### Patient Dying and Death Imminent

It is also argued that the *prima facie* obligation to medically treat can be overridden if the patient is in danger of *imminent* death. That is, if it can be determined that a patient's death is imminent and the condition irreversible, modes of treatment such as resuscitation, respiration and presumably ANH, become optional. The death of the patient is foreseen but not directly intended. The withdrawal of treatment, in this instance, does not induce a fatal pathology but, rather, allows a fatal pathology to take its natural course — the patient is allowed to die rather than being killed. Such treatment is said to be *extraordinary* and, therefore, morally optional.

The medical status of the comatose patient would seem to suggest that some forms of medical treatment may sometimes be optional. Those comatose patients, for example, who have seriously impaired cough, gag and swallow reflexes frequently develop serious and often fatal respiratory infections (the fatal pathology), often within a few weeks or months of the onset of coma. The fatal pathology, if allowed to run its natural course, will result in the death of the patient, independently of whether ANH is continued or withdrawn. Thomas J. O'Donnell, in reflecting on those comatose patients who *do* have a combination of incurable pathology, permanent unconsciousness and the inability to take food and water normally, argued: ". . . artificial provision of nutrition and hydration could be withheld or withdrawn either because the burden of continuing treatment would be disproportionate to the benefit, or because their continuation would be judged not to be clinically significant or therapeutic."<sup>55</sup> This seems consistent with Diamond's point about incurable pathology; death will ensue independently of ANH and its effects.<sup>56</sup> The withdrawal of *extraordinary means*, including artificial or medically provided nutrition and hydration, could be justified as optional, argues Beauchamp and Childress, as they are no longer curative and merely prolong the act of dying.<sup>57</sup>

However, the medical facts also suggest that some comatose patients and most

PVS patients are neither dying nor do they sustain sufficient damage to the cough, gag and swallow reflexes to justify termination of treatment. They may die sooner or later from a variety of other less predictable causes. Indeed, as we have seen, the PVS patient far from dying, may, in fact be quite robust and survive for many years. In these cases, the early withdrawal of treatment, including that of ANH, is not easily justified. However, there is little doubt that the AMA's recommendation regarding the withholding of nutrition and hydration from those patients in irreversible coma for whom death is not imminent, and specifically, PVS patients, has influenced the thinking of some commentators on this issue.<sup>58</sup> Diamond, in a strongly worded response, pointed out the existence of three fundamental fallacies in the rationale developed by the AMA for the withdrawal of ANH from PVS patients.<sup>59</sup> First, "the allegation that the fatal pathology, in patients with persistent vegetative state is the inability to swallow, (second), the interpretation of the discontinuation of feedings as an unwillingness to 'circumvent' this fatal pathology, and (three), the requirement that the patient be capable of 'cognitive-affective' function in order to pursue the purpose of life and the implication that a life devoid of cognitive-affective function at a certain unspecified level is a life unworthy to be lived."<sup>60</sup> We believe the medical facts of PVS as presented here and elsewhere,<sup>61</sup> support Diamond's first two fallacies and Smith has recently exposed the third fallacy.<sup>62</sup>

Finally, the impreciseness of the phrases *terminal condition* or *terminally ill* and the lack of a clearly identifiable *fatal pathology*, particularly with the PVS, increases the possibility of judgmental error and may lead to killing rather than allowing the patient to die. No matter how compassionate the motive, in the absence of a fatal pathology, the withdrawal of ANH is killing and the public policy on this, as Horan points out, "is embodied in the laws of homicide."<sup>63</sup>

### **Patient Burdens Outweigh Benefits**

Beauchamp and Childress also argue that, even if a patient is not dead or dying, "medical treatment is not obligatory if its burdens outweigh its benefits to the patient. When patients are not irreversibly dying and their deaths are not imminent, medical treatment may be optional even if it could prolong life for an indefinite period."<sup>64</sup> The net benefit over burden argument seems, on the surface, to make good sense with respect to the PVS and comatose patient. Why do something which will not make any difference? The implication is if it is not effective, then it is futile.

Lussier questions this *effective* perspective of the net benefit/burden calculus, What is it that we want the treatment, that is, ANH, to effect (this assumes medically provided nutrition and hydration by, for example, tubing, to be a form of medical treatment)? In order to be effective, does a treatment have to cure an underlying condition, or, can it be either palliative, or intended to maintain some part of a person at his or her present level without altering the underlying disease?<sup>65</sup> Some commentators answer the former in the affirmative, in that, when the provision of nutrition and hydration improves these levels and the patient's underlying condition does not improve, then continued provision of ANH is optional.<sup>66,67</sup> This argument is not particularly compelling. There are many instances where management includes both treatment aimed at curing as well as those designed to stabilize,

ameliorate or compensate for either the intregenic effects of the attempt to cure or the effects of the underlying condition itself on body systems. For other commentators, the provision of ANH not only serves to support and maintain the patients' present physiological condition, in which sense it may constitute an improvement, but to do otherwise would amount to killing in those cases where the relevant disease process was insufficient to cause death.<sup>68,69</sup>

McMillan questions our sincerity when she asks: "But can we honestly say that artificial feeding procedures *always* represent the most compassionate and respectful response to a patient? If we insist that we must *always* feed a patient, no matter what his condition or his desires are we really acting in a way which is consistent with the Catholic tradition? Or is it not often the case, rather, that those who order and administer feeding regimes are doing so because they dare not discontinue them, and even that they dare not ask themselves whether these procedures are not from the patient's point of view, futile or excessively burdensome?"<sup>70</sup> This issue of whether the medically provided nutrition and hydration can become excessively burdensome to the patient and, therefore, constitute morally optional extraordinary means, is a relative non-issue with the permanently unconscious. The medical reality, as we now know, is that the experience of pain and suffering are attributes of consciousness. It is simply not possible for the permanently unconscious patient to experience the burdens of pain and suffering as these require the integrated functioning of both the brainstem and the cerebral cortex. The provision of ANH to these patients can never be perceived by them as a burden.

The withholding or withdrawal of ANH on the grounds that the permanently unconscious patient is living a life not worth living is also difficult to justify. Quality of life and capacity to relate concepts, though promoted by some in particular cases, for example, anencephaly,<sup>71</sup> are so vague and ambiguous that most commentators dismiss their relevance to serious ethical debate.<sup>72</sup> We condemn them, as do Beauchamp and Childress, as, "irrelevant slogans that mislead rather than illuminate."<sup>73</sup> The withdrawal of ANH from permanently unconscious patients on the basis of quality of life judgements made not by the patient but by others, would, for both the PVS and comatose conditions, constitute killing the patient. What can be done for the patient who is not dying, but who is permanently unconscious and almost certainly being fed and hydrated by artificial or medical means? In the case of the PVS patient, provided nutrition and fluid is made available, he or she will live, and live in some cases for several decades. If they are withdrawn from the patient, death is certain to occur. The provision of ANH is neither expensive to maintain nor burdensome for the patient to bear and is successful in achieving what it aims to do — keep the patient alive. Other things being equal, there is no morally compelling justification for withholding or withdrawing nutrition from an otherwise healthy permanently unconscious patient.

There may be, however, morally compelling arguments against the use of antibiotics to treat serious respiratory infections, for either PVS or comatose patients, even though death may result from non-treatment. Keeping the patient alive with its attendant medical care and necessary nursing support is very costly and is borne either by the community or the patient's family, depending upon

the systems of medicare or health insurance available in that society. Even without a comprehensive theory of "justice as fairness" in the allocation of health care resources, it could reasonably be argued that other patients — patients who can benefit in substantial ways from the time and resources freed if the permanently unconscious patient dies — may have a greater right to the scarce health resources. Although an adequate discussion of "justice as fairness" in the allocation of health resources is beyond the scope of this paper, it remains an issue in urgent need of serious debate in the context of the PVS patient.

### Can the Ethical Problem be Defined Away?

Wikler comments that, when decisions about treatment options for those in a persistent vegetative state have to be made, those options tend to be considered as though they are dying patients. Although it may be intuitively difficult, he argues, to accept that the entity in the persistent vegetative state — still a living body — is not the patient, the time may have come to consider expanding the definition of death to include those in persistent vegetative states.<sup>74</sup>

The medical fact, however, is that these people are *not* dying, at least not as a direct result of their vegetative state. As a result, it is difficult on medical, logical, or moral grounds to act on the premise that they are dying. If we cannot act on the premise that they are dying, then we must conclude that it is a moral duty to treat them, at least minimally. Mullooly argued the need for "minimal" means as a way of withholding nutrition and hydration from those in a vegetative state:

In any discussion of ordinary and extraordinary means of prolonging life in terminal illness, it seems reasonable and necessary to introduce a category of "minimal means" which must always be used, because to withhold them when they can be received is equivalent to a positive act of destruction. By these we mean food and water taken normally as distinct from the clinical modalities of IV needles, gastric tubes, hyperalimentation formulae, etc.<sup>75</sup>

While Mullooly supports the view that the burdens of artificial nutrition and hydration could, on occasions, outweigh the benefits for the patient, thereby rendering the means "extraordinary," he clearly opts for the general position that normal feeding is, by its nature, an ordinary means of treatment. Clearly, this is the norm and, as such, is what must be applied in normal circumstances to any patient who is in an undying state. The burden of proof lies with those who may wish to do otherwise in a particular instance.

Certainly, the above represents the official position of the Catholic Church, which is that feeding the patient is an essential part of ordinary care and amounts, therefore, to obligatory means. GRIESE, in amplifying the Church's position, defines ordinary care as including ". . . hygiene and cleanliness, comfort medications, warmth and proper temperature, TLC (tender loving care), and, of course, the stuff of life, nutrition and hydration."<sup>76</sup>

These writers concur with the above view. To allow for exceptionality through the overwhelming case where burden outweighs benefit is one thing. To accept this as the norm in every case of the persistent vegetative state is another thing altogether. Again, GRIESE expresses the view well:

"... the feeding of the sick and helpless, as a general rule, remains a part of ordinary care even if it is administered by artificial means such as nasogastric intubation, gastrostomy process, peripheral intravenous feeding on temporary basis, etc. — admittedly, the artificial feeding process can constitute recourse to an extraordinary means in particular cases (is it useless, excessively burdensome, etc.), but the fact remains that tube feeding to sustain life does not (again, as a general rule) involve excessive difficulty."<sup>77</sup>

In conclusion, the ethical problem cannot be defined away. Those in persistent vegetative state must be treated as undying, because, as a general rule, that is the medical fact. While curative treatment, as well as sophisticated and costly palliative treatment can reasonably be argued against on the grounds of a number of well-defined ethical principles, withdrawing or withholding the stuff of life cannot. While it might not suit an expediently-minded and recession-bound society to admit it, the cost of ANH to these people is not only justified, but the least we need to do in order to maintain the most basic levels of due care on which the reputation of the medical profession depends.

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