

Withholding nutrition from the severely incapacitated: Compassion for the incurable, or euthanasia by omission?

Maria Korp, a woman aged 50 and mother of two children, suffered oxygen loss to her brain following an attempted homicide 5 months ago, resulting in severe brain damage. The Public Advocate in the State of Victoria, appointed as her medical guardian, directed the medical staff to stop feeding her through a tube in her stomach, meaning she will die within the next couple of weeks.

In May 2003, Victoria's Supreme Court ruled that a feeding tube could be removed from the stomach of a 69-year-old woman known as BWV, allowing her to die. The woman had lain in a persistent vegetative state in a nursing home for three years, unable to communicate, and was being kept alive by a feeding tube that delivered food, water and medication. The court ruled that artificial nutrition and hydration was a medical procedure, not palliative care, and that as such there was a right of refusal.

Terri Schiavo, aged 41, spent 15 years in a vegetative state after suffering brain damage. She died nearly two weeks after her husband won the right to have her feeding tube removed following a court order. Her husband won a bitter legal fight with her parents and the case sparked a national right-to-life debate in the USA.

These cases raise the question of what is appropriate medical care for severely brain-injured patients and should medical treatment be withdrawn to speed up death? Is this euthanasia by omission or compassionate care for someone who has no hope of recovery? What is appropriate medical care for these patients? Is the use of feeding tubes, to provide nutritional support, an "extraordinary" medical procedure that should be withheld? Are there any circumstances where nutrition should not be given to such a person?

This complex topic can be divided into four questions:

- What is PVS and is it equivalent to saying that person is dying?
- Is a "person" in a persistent vegetative state still a person?
- Is the provision of nutrition a medical procedure?
- In what situation(s) would the provision of nutrition be futile or harmful?

1. What is the Persistent Vegetative State (PVS)?

The persistent vegetative state (PVS) is defined as a permanent and irreversible condition of unconsciousness in which there is: (a) the absence of voluntary action or cognitive behavior of any kind; and (b) an inability to communicate or interact purposefully with the environment. The patient has a sleep-awake pattern, but responds to stimulation only in an automatic or reflex way and shows no evidence of meaningful response to the environment. The damage involves those parts of the brain that are necessary for cognitive function, speech and other forms of communication, voluntary control of movement, swallowing, and voluntary control of bodily functions. The 'lower' parts of the brain that control essential organ functions such as breathing, circulation, and the digestive processes remain intact.

The diagnosis of PVS requires repeated medical assessments by trained specialists over a prolonged period of time. This is necessary to avoid misdiagnosis by

inexperienced doctors and the possibility of delayed recovery months after the initial injury. PVS should be distinguished from “brain death” which implies the permanent and irreversible loss of all – not just some – brain function.

The majority of patients with severe and permanent brain damage die within weeks or months of the initial illness. Death is usually the result of delayed complications such as infection (in the lungs or kidney), by heart failure or breathing failure. When these complications of PVS occur it often impossible for any medical therapy (including nutrition, antibiotics or life-support machines) to reverse the dying process. If the patient is dying of irreversible injuries then it is appropriate to consider removal of futile therapy (such as nutritional support) that would otherwise prolong the dying process.

Is the diagnosis of PVS synonymous with dying?

Some patients with PVS do survive and can be kept alive for many years through the provision of good nursing and medical care, including nutrition. However, their life expectancy is greatly reduced, with the average ranging from two to five years. The length of survival depends in part on how actively the medical complications of PVS are treated. Survival beyond 10 years is unusual. Although PVS may be considered to be a terminal illness it is not synonymous with dying. Deterioration in the physical condition of the patient is universal but the process may be sufficiently slow for some patients to survive for many years, as in the cases above.

2. Is a “person” with a PVS still a person?

Severe brain damage results in the loss of many qualities that are held to be unique to, or at least more highly developed in, human beings. Some of the human characteristics that are permanently “lost” or absent in PVS sufferers include self-awareness, self-expression, abstract thought, creativity, emotions, communication, and socialization. Does this equate to the loss of personhood? Is such a “person” no longer a human being? Are there any unique characteristics that distinguish humans from animals?

If these “lost” qualities truly define the unique characteristic(s) of human beings then a patient with a PVS is no longer human, and the “person” has, in fact, died. Therefore it would be ethical and humane to withdraw treatment – including nutrition – and allow the natural process of dying to proceed. To continue nutritional support and prolong the dying process, under this perspective, would be inhumane.

The biblical perspective is however radically different. The uniqueness of man is independent of any intrinsic qualities (as mentioned above.) In the biblical view of man an external dignity is bestowed upon him by his Creator. “God made man in his own image” means that we were created to be in a personal relationship with Him. The originally created relationship was a positive one – a relationship of friendship and honour. This is the uniqueness of man. When man decided to go his own way and ignore God, this relationship (our essential human quality) did not cease to exist, it simply became a negative relationship – a relationship of enmity and dishonour. Instead of destroying mankind, the Creator reinforces this alien dignity of human

beings by sacrificing His own Son in order that the original relationship might be restored.

If the biblical view is correct then we must consider even the person with PVS as a person created by God and still in relationship with Him, albeit without the ability to express this. The loss of other human “qualities” (mentioned above) is tragic and not part of God’s original plan, but does not remove the essential humanity or personhood from the patient with PVS. In this situation we should treat such persons with human dignity they deserve, irrespective of their physical and mental disabilities. Since access to food and water is a basic need and “right” of all human beings, the provision of nutrition is appropriate and the “right” of even the severely incapacitated, including those in a PVS.

It is dangerous to base end-of-life decisions on our own perceptions of “quality of life.” We may not wish to ever be in such a tragic condition but it is fallacious to assume all patients would think the same way. Many who have suffered permanent severe brain injury, but are still able to communicate (non-verbally), have indicated a will to continue to live. We cannot assume that the absent response (of the PVS sufferer) is equivalent to assent to withdrawal or withholding therapy.

3. Is the provision of nutrition a complex medical procedure?

Medical technology gives us the means to keep patients with severe brain injury alive. Prior to the 20th century very few patients with severe brain injury would have survived for very long. The technology that now enables some to survive and recover from their initial brain damage also makes it possible for others to survive who will never recover brain function sufficient to restore communication or self-awareness. PVS is, in one sense, an unfortunate byproduct of modern medical technology.

Through simple medical techniques survivors with severe brain injury can be kept alive for months or years. Improvements in medical and nursing care help to prevent or delay complications, such as starvation, that would otherwise lead to early death. This provides time (3-12 months) for the brain to recover some function.

There are two commonly used methods for the delivery of food into the stomach of a person who cannot eat or swallow. Both use specially designed tubes that are placed directly into the stomach; both involve medical expertise and equipment; and both procedures are associated with a small risk of death or life-threatening complications.

The most commonly used technique involves the insertion of (naso-gastric) tubes that can be passed through the nose and (down back of the throat and through the oesophagus) into the stomach. Vitamised or liquefied food and medications can then be delivered directly into the stomach. This procedure requires some training and skill, utilises specially designed tubes, and must be performed by a nurse or doctor. The discomfort during and after insertion is minimal and anaesthesia is not required.

Serious or life-threatening complications from naso-gastric tubes, although rare, can occur. During insertion it is possible to cause bleeding from the nose or throat, or misplacement of the tube into the lungs resulting in breathing difficulty and

pneumonia. Death during the procedure has been reported, but the reported risk is low - less than 1 in 300. Later complications are more common and include infection (sinusitis, pneumonia), ulceration and bleeding (from the nose, oesophagus or stomach), or dislodgement of the tube (necessitating its reinsertion.) For these reasons this method is used for patients who only require short-term feeding (eg weeks or months.)

An alternative technique is used for patients who require long-term (months or years), or permanent, tube-feeding. The technique of percutaneous endoscopic gastrostomy (PEG) tube insertion requires more specialized equipment and training and is performed by medical specialists. The procedure involves the insertion of a tube into the stomach through a small incision made through the skin (and muscle) in the upper part of the abdomen. Although technique is widely used and safe, there is still a (1 in 30) risk of serious or life-threatening complications (peritonitis, hemorrhage, pneumonia, wound infection) and a small (less than 1 in 100) risk of death – similar to the risk of a patient dying after open-heart surgery.

The amount and content of food delivered into the stomach (by any tube) is also important. Nutritionally balanced liquid formulations are used, and the rate and volume must be carefully monitored. This is done under the supervision of qualified dietitians. Too little or too much food, or an imbalance in nutrient content, can result in serious complications, such as malnutrition, vomiting, or pneumonia.

In summary, the provision of nutritional support to patients with severe brain injury (such as PVS) involves medical procedures that require medical training and specially designed equipment. These procedures carry a small but significant risk of serious complications and even death. Whether or not these medical procedures (to safely provide nutritional therapy) are beneficial, harmful or dangerous will depend upon the circumstances of each case. In the majority of cases, however, these risks are low.

Two medical perspectives can be considered. It is possible to argue that these simple, low-risk, feeding tubes fall into the category of standard nursing and/or palliative care. Since access to food and water is a basic human “right” it is reasonable to perform these minor procedures necessary to provide nutrition to those unable to eat or swallow. Alternatively these feeding tubes may be considered as “extraordinary”, life-supporting, medical interventions beyond the scope of basic nursing and palliative care. As such they may be medically and ethically withheld, or withdrawn.

Many health care professionals and legal systems in most North American states, and in the State of Victoria here in Australia have formed the later view. The Catholic Church has also reached a consensus that withholding or withdrawing artificial feeding is morally acceptable, at least in some cases.

4. Is nutritional support futile, harmful, or unduly burdensome?

The absence of food and water will eventually lead to death. For this reason access to food and water is considered a fundamental human right. The duration of survival

depends upon a number of factors, but most patients with severe brain injury will die within 1-2 weeks without food. Death from starvation is not necessarily unpleasant or painful as long as simple comfort measures (eg. moisture in the mouth) are maintained.

It is important to also point out that optimal nutritional support will not necessarily prevent death. Despite optimal medical and nursing care of severely brain-injured persons they may develop serious complications, such as pneumonia, from which they may not survive. Medical treatment, including nutrition, antibiotics, and even life-support therapy, may not be able to prevent death. In our experience if a person is dying (from a disease process other than malnutrition or starvation) it is unusual for continued nutritional support to unduly prolong the dying process or delay death.

When it is clear that the dying process has commenced (and cannot be reversed) then it is reasonable to consider the withdrawal of treatment (including nutritional support) because it is futile, i.e. it will not alter the eventual outcome, and may cause distress or discomfort, eg. vomiting. It may also be futile and harmful to insert (or re-insert) a feeding tube into the stomach, or to continue to provide food, because the risks or complications (as mentioned above) outweigh the potential benefits. These decisions are a matter of clinical judgment for experienced and qualification medical specialists.

Why Is It So Complex?

Why is this issue so complex? Why are there so many differences of opinion? Why do we have doubts no matter which viewpoint we choose? Why is there no obvious universal “right answer”? Why do the advances in medical knowledge and medical technology appear to make the issues more complicated, instead of less complicated? Why doesn't the bible make it clear what we should do in these situations?

Most ethical philosophies are unable to explain why ethical dilemmas exist! The biblical perspective at least provides us with an explanation: the world is not the way it was originally intended. The world is disrupted and distorted by the intrusion of Evil that was not part of the original plan. This ‘distortion’ provides the milieu for disease, tragedy, and insoluble ethical dilemmas. At times we face unavoidable questions for which there is no clear-cut answer, no right answer – we are forced to decide between two wrongs rather than right and wrong.

For the Christian, in such situations as this, there is a burden and there is a freedom. The burden is that we are faced with a situation where we are forced to choose between shades of gray and not between black and white. The freedom for the Christian is that we are not alone, that God understands our predicament, that He calls us to decide and step forward in faith, that He promises to walk with us and share our difficult times, that we live under His love and forgiveness, and that we are no longer bound by guilt.

Conclusion.

We should respect the severely brain-injured person (including those in a PVS) as

human beings created and loved by God and endowed with an “alien dignity”. As such they are entitled to basic human rights such as access to food and water. Nutritional support involves relatively simple and readily available medical techniques.

We should also acknowledge that the provision of nutritional support does require invasive medical procedures, medical expertise, and specialized equipment, and does carry a small but significant risk of harm. Whether or not the provision of nutrition via a feeding tube is an invasive medical intervention and an “extraordinary” form of life-support, is unclear. In some circumstances it is a simple and safe procedure; for some, the risks and complications will result in unnecessary harm; whilst in other circumstances the provision of nutrition is futile.

Withdrawal or withholding of nutritional support should be considered in the situation where (a) the patient is dying; (b) the risks or complications of nutritional support outweigh the potential benefits; or (c) it is contrary to the previously expressed wishes of the patient. These decisions require expert medical advice, and the discussion should always involve the family and next-of-kin. Withdrawal or withholding of nutritional support for reasons of expediency or persistent disability is euthanasia by omission.

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4/8/05