not exist' (Rom 4:17). While, though, crucifixion is what makes a Christian, this should not be interpreted in the sense that Christian discipleship has no place for a voiced protest against God. The cry to God for help expresses the concrete reality of human existence, and trusts in a new divine action in response to the human cry for help. Lament yearns for something new, it hopes in an unforeseen and better future, and it acknowledges the human wrestling with God. This means that what practical forms our compassion towards the victims of child sexual abuse should take, and what forms they should take towards all the other persons affected by such crimes, remains something to be worked out by the faithful, under the guidance of the Spirit, who breathes new life into the church and the world.

This article has attempted to show the invaluable import of the lament speech form not only in respect of the Royal Commission specifically, but in respect of the faithful more generally, which is vital to ensuring that Christian life, worship, and ministry do not become shallow, evasive, and disconnected from the trials, tribulations, and sufferings of a world ‘groaning’ (Rom 8:18-25) for its final salvation. In the New Testament, Paul in particular holds fast to the idea that ‘groaning’ is inevitable under the conditions of this earthly life lived in time and history. It is not the case that lament is invalidated in the New Testament; rather, lament is re-evaluated as a positive expression of our longing for the fullness of salvation in the risen Lord Jesus Christ. Without the practice of lament that gives honest expression to our groaning for final salvation, it is difficult to see how the faithful will be adequately equipped to respond effectively to Pope Francis’ call for a new evangelisation based on our willingness and readiness ‘to touch the suffering flesh of others’.

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46. Evangelii Gaudium, 270.

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Understanding the Persistent Vegetative State and the Ethics of Care for Its Patients

Norman Ford*

In 1972 Brian Jennett1 and Fred Plum2 recommended the term ‘persistent vegetative state’ (PVS) to describe a state of continuing ‘wakefulness without awareness’, which can follow a variety of severe insults to the brain. Their description of the syndrome has stood the test of time, but PVS continues to be a source of medical, legal, and ethical debate.4

America’s Eminent Scholar, Joseph Pons, on PVS

Comatose states can ... evolve into a vegetative state ... which is labeled persistent once it lasts more than a month. It is considered

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1. Bryan Jennett (1926–2008) was a professor of neurosurgery who established Glasgow as a world centre in the speciality; he made major advances in the care of patients that led to improvements in head-injury treatments.
2. Fred Plum, MD, university professor, Weill Medical College, Cornell University.
4. National Health and Medical Research Council (Australia), Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State (Canberra: NHMRC, 2008), defines post-coma unresponsiveness (PCU) on p. 4 as: ‘a state or condition in which a person has emerged from coma to the extent that he or she is observed to have sleep/wake cycles over a period of time but no purposeful responses to stimuli’. Further: ‘Responsiveness may gradually return in some people, leading to MRS [minimally responsive state] or even better, although improvement may be very slow. Some recovery may be achievable but full recovery is highly improbable’. The guidelines are available at https://www.nhmrc.gov.au/guidelines-publications/681-e82.
permanent after three or 12 months depending upon the initial injury. If the injury is from anoxia (oxygen deprivation), as would be the case in a cardiac arrest or drowning accident, a vegetative state persisting for three months is considered permanent. In contrast, a vegetative state resulting from a traumatic brain injury, such as a motor vehicle accident, a vegetative state persisting for three months is considered permanent....

The different time courses to a permanent vegetative state relate to the nature of the injury. The potential for recovery for a traumatically injured brain exceeds that of the anoxically injured brain. This differential degree of recovery from anoxic injury helps explain why it takes longer for clinicians to conclude that a traumatic injury has resulted in a permanent vegetative state. If a vegetative state has yet to become permanent, a patient may move into what has been described as minimally conscious state [MCS]. MCS patients demonstrate unequivocal but fluctuating evidence of awareness of self and the environment.5

Again Fins:

Diagnostic errors of omission or commission have the potential to either perpetuate false hope in the case of the permanently vegetative or to blind us to the recuperative potential of minimally conscious patients.... Where it was once presumed that severe brain injury was invariably as dire as the vegetative state, we now know that prognostic outcomes can be variable. Therefore, it is increasingly inappropriate to view brain injured patients as untreatable. To pursue therapeutic possibilities without engendering false hope, it is critically important to diagnose brain states as precisely as possible in order to balance burdens and benefits.6

The National Institute of Neurological Disorders and Stroke, on Coma

Coma may occur as a complication of an underlying illness, or as a result of injuries, such as head trauma.... Even though those in a persistent vegetative state lose their higher brain functions, other key functions such as breathing and circulation remain relatively intact.... Individuals may even occasionally grimace, cry, or laugh. Although individuals in a persistent vegetative state may appear somewhat normal, they do not speak and they are unable to respond to commands.

Once an individual is out of immediate danger, the medical care team focuses on preventing infections and maintaining a healthy physical state. This will often include preventing pneumonia and bedsores and providing balanced nutrition. Physical therapy may also be used to prevent contractures and deformities of the bones, joints, and muscles that would limit recovery for those who emerge from coma.

The outcome for coma and persistent vegetative state depends on the cause, severity, and site of neurological damage. Individuals may emerge from coma with a combination of physical, intellectual, and psychological difficulties that need special attention. Recovery usually occurs gradually, with some acquiring more and more ability to respond. Some individuals never progress beyond very basic responses, but many recover full awareness.... A coma rarely lasts more than 2 to 4 weeks. Some patients may regain a degree of awareness after persistent vegetative state. Others may remain in that state for years or even decades. The most common cause of death for someone in a persistent vegetative state is infection, such as pneumonia.7

Patients in PVS are unconscious, but have sleep-wake cycles. When awake, they may appear to be alert, they are not aware of their surroundings. This distinguishes them from patients in coma who are unconscious because they lack both wakefulness and awareness.... patients in PVS retain autonomic brain stem functions, i.e. normal control of involuntary muscles, and most PVS patients do not require mechanical ventilation....

Diagnosis of PVS is based on repeated physical examinations over time; neurodiagnostic tests, such as electro-encephalography or cerebral metabolic studies on the process a body uses for energy, may supply supporting information.... PVS patients require daily skin care and attention to personal hygiene, with a range of motion therapy to slow the formation of limb contractures in addition to artificially administered nutrition and hydration.8


6. Ibid.


Caring for PVS patients can be emotionally demanding. They maintain irregular sleep-wake cycles; most show reflex eye movement, but they do not actively track moving objects or move their eyes voluntarily. PVS patients can usually move their limbs or trunk; some utter grunts, or other vocalizations, many vary their facial expressions, and some may even smile or shed tears, but these actions are neither voluntary nor purposeful...

Initial vigorous treatment may be appropriate because of the time needed to make a diagnosis of PVS with a high degree of medical certainty. Once the diagnosis has been established, difficult decisions must be made about what level of care is appropriate, including decisions about withholding or withdrawing life-sustaining treatment. Families and surrogates facing such decisions should receive appropriate psychological support.  

Australia's Prof. Stephen Davis, President, World Stroke Organization, says 'the persistent vegetative state indicates a duration of 1 month or longer and permanent vegetative state has been used for more than 3 months duration in non-traumatic cases and more than 1 year in traumatic cases'. 10 Australia's National Health and Medical Research Council in 2008 stated that 'the term post-coma unresponsiveness (VS) may generally be applied to patients emerging from coma in an apparently wakeful unconscious state in which there is: a complete lack of responses that suggest a cognitive component; preservation of sleep-wake cycles and cardio-respiratory function; and partial or complete preservation of hypothalamic and brain-stem functions'. 11

Belgian scholars have said that patients in coma, vegetative state / unresponsive wakefulness syndrome, and in minimally conscious states pose medical, scientific, and ethical challenges. As patients with disorders of consciousness are by definition unable to communicate, the assessment of pain, quality of life, and end-of-life preferences in these conditions can only be approached by adopting a third-person perspective. Surveys of healthcare workers' attitudes towards pain and end of life in disorders of consciousness shed light on the background of clinical reality, where no standard medical-legal framework is widely accepted. 12

11. National Health and Medical Research Council (Australia), Ethical Guidelines, 4.

The Nursing Care of Patients with Disorders of Consciousness

Ana Puggina is a staff member of the Research Group about Communication in Nursing at the School of Nursing, University of São Paulo, Brazil. She began as a registered nurse for some time before she did a three-month course in investigator science at Cambridge University and subsequently graduated with her PhD. She soon developed an international reputation for the care of PVS patients with mental disorders, especially post-coma unresponsiveness. 13 She knows quite well that nursing care of these patients requires specific knowledge, as well as competence and skills for the planning and performance of duties of care and for the handling of non-communicative patients. It is most important that professional nurses frequently look for enhancements and updates to enable them to work better with these patients.

The combined use of behavioral and neuroimaging assessment techniques seems to be particularly promising for disentangling, on the one hand, impaired consciousness, and, on the other hand, aphasia (a disorder of language affecting the generation and content of speech and its understanding, but not a disorder of articulation). Rigorous behavioral assessment is usually sufficient to establish a patient's level of wakefulness and awareness. But it is becoming apparent that in some patients damage to the motor system may prevent overt responses to commands, even though the cognitive ability to perceive and understand commands may remain intact.

Despite the importance of diagnostic accuracy, the rate of misdiagnosis of the vegetative state apparently has not substantially changed in the past fifteen years or more. As Puggina et al. say: "This is most likely because generally this area does not involve patients who will be cured; therefore there is little or no motivation to research deeply into this area. This [their] study is important because it highlights this lack of research". 14

The clinical assessment of these patients is very complex and frequently depends on subjective interpretations of the observed spontaneous behaviour. The objective assessment of consciousness is difficult. Hence, clinicians need to infer awareness by the evaluation of motor activity and the following of commands. Assessment of awareness is not a matter of all or nothing. Recovery of awareness may be a very gradual process, with occasional great leaps forwards, but more often with unstable changes, and sometimes setbacks. For the patient recovering from coma, it is of utmost importance that nurses adapt their assessment to the level of awareness in which the patient currently is. Nurses and healthcare workers should also know the difference between reflex movements.

(such as blinking one's eyes), on the one hand, and eye tracking and voluntary responses to pain, on the other.

**Care and Management**

Patients with disorders of consciousness are challenging for daily nursing care and management in both acute and chronic phases, which includes such aspects as pain assessment, treatment, prevention of skin injuries, management of ulcers, and the maintenance of respiratory and cardiovascular functions. Nurses need to keep the best possible physical status of their patients as it maintains the dignity of the patients and satisfies the wishes of relatives that patients be well cared for. Obviously nurses and doctors ought to work together harmoniously and share their insights for the benefit of their patients and themselves—it's forever a learning experience!

**Nurses' Communication with the Patients**

A study attempted to assess the attitudes and practices of five intensive care nurses concerning verbal communication with unconscious patients. The results indicated that intensive care nurses spend on average five per cent of their time verbally communicating with unconscious patients, informing them about immediate procedural matters or providing them with reassurance. The average time devoted by nurses to verbal communication was 4.5 minutes for four hours of observation. This highlights the need for formal support systems and continued education for nurses about the benefits of verbal communication. Nurses' casual conversations among themselves need to be carefully monitored to avoid their making any negative comments that could offend patients who might hear them.

**Nurses' Communication with Families**

Relatives initially find it hard to accept the reality of a close friend being in a situation where conversation is cut off for a time, and maybe forever. Their shock is hard to get over and to live with. Conversations occur in the hope of some communication being achieved. Relief may be given by holding a relative's hand. A diagnosis needs to be made and the resulting difficult decisions must also be made about the appropriate level of care needed, including decisions about withholding or withdrawing life-sustaining treatment. Nurses also prepare relatives to receive confirmation of a loved one having to live with PVS.

Patients' family members want accurate information provided by doctors and nurses in an understandable manner whilst still leaving room for their cherished hopes. Information given that is more positive than warranted is not appreciated at all: it may lead to false hopes, increased distress, and loss of trust in healthcare professionals. Sustaining the hope of family members with the truth is required. Promoting hope based on truth, accompanied by kindness, is the best way forward for patients' family members. Families and surrogates facing such decisions should also receive appropriate psychological support.

Puglisi et al. sum it up well: Management of severely brain-injured patients constitutes a social, economical, and ethical dilemma as well as a real challenge for the medical staff, as specific expertise is required. The aim of their research had been to explore the aspects of nursing care for patients recovering from coma such as the difficulty of diagnosis, residual perception, clinical assessment, care and management, and communication with patients and their families. Again, they say that daily management and communication with patients requires attention and training by health officials, as well as communication with the families of these patients who require more sensitivity and full involvement by the team. Finally, it is important to establish a nonverbal basic communication with patients and to avoid conflicts with their families—good care optimises a chance of recovery.

**Communication with Non-Responsive Patients**

Functional magnetic resonance imaging (fMRI) is a technique for measuring brain activity and works by detecting the changes in blood oxygenation and flow that occur in response to neural activity. When such changes occur, a part of the brain becomes active, resulting in a greater supply of oxygen by an increased blood flow. This activity can be mapped by fMRI, showing the part of the brain that is activated as well as other parts of the brain involved in all mental activities. fMRI has its benefits: being non-invasive and not emitting any radiation, it is safe for human subjects, and is not difficult to use for imaging normal brain functions.

fMRI is suitable for imaging normal brain functions, including memories and learning, which will be of benefit especially for psychologists. In recent years it has provided new insights for investigating how memories, pain and emotions are formed. The magnetic signal from hydrogen nuclei in water (H_2O) is detected by fMRI. The key to fMRI is that the signal from hydrogen nuclei varies in strength depending on the surroundings. This provides a means to discriminate between grey matter, white matter and cerebral spinal fluid in structural images of the brain. Oxygen is delivered to neurons by haemoglobin in red blood cells. When neuronal activity increases there is greater demand for

16. Puglisi et al., 'Nursing Care of Patients', 260.
17. Ibid., 268.
oxygen and the local response is an increase in blood flow to regions of increased neural activity." This variation in neuronal oxygen uptake is depicted in the following images: on the left are resting neurons; on the right, activated ones.

The difference in magnetic properties leads to small differences in the magnetic resonance signal of blood, depending on the amount of oxygen used. Since blood oxygenation varies according to the levels of neural activity, these differences can be used to detect brain activity. This form of fMRI is known as blood oxygenation level dependent (BOLD) imaging.

The combined use of behavioural and neuroimaging assessment techniques are promising for disentangling apalasia (total or partial failure of development of an organ or tissue) and impaired consciousness. fMRI will substantially increase how much doctors and nurses understand patients with severe brain damage and will reduce the diagnostic errors in relation to patients with disorders of consciousness. Rigorous behavioural assessment is usually sufficient to establish a patient's level of wakefulness and awareness.21

Lorina Naci and Adrian Owen, of London, Ontario, give a brief account of the results of their work in ‘Making Every Word Count for Nonresponsive Patients’22

We present a novel fMRI technique that relies on selective auditory attention for detecting conscious awareness and communicating with behaviourally nonresponsive, brain-injured patients. We demonstrate that 3 patients with disorders of consciousness, 2 of whom were diagnosed as being in a minimally conscious state and 1 as being in a vegetative state, were able to convey their ability to follow commands inside the fMRI scanner by attending to some events while ignoring others, in accordance with instructions...

To our knowledge, we show for the first time that a patient who had been in a vegetative state for 12 years was able to selectively pay attention to some external events in his environment while ignoring others, according to command. Despite his [the patient’s] diagnosis, the fMRI approach allowed the patient to establish interactive communication with the research team in 4 different sessions. The patient’s brain responses within specific regions were remarkably consistent and reliable across 2 different scanning visits, 5 months apart, during which the patient maintained the long-standing vegetative state diagnosis. For all 4 questions, the patient produced a robust neural response and was able to provide the correct answers with 100% accuracy. The patient’s brain activity in the communication scans not only further corroborated that he was, indeed, consciously aware but also revealed that he had far richer cognitive reserves than could be assumed based on his clinical diagnosis. In particular, beyond the ability to pay attention, these included autobiographical knowledge and awareness of his location in time and space....

Our results suggest that [the] fMRI technique may offer novel opportunities to entirely behaviorally nonresponsive patients who cannot use existing methods to communicate. Moreover, this technique assesses selective attention, a basic building block of human cognition, which underlies many complex faculties, including reasoning and, more broadly, information processing. Hence, for any behaviorally nonresponsive patient who can use selective attention as a means for communicating, this method may provide initial screening for more complex abilities, the presence of which may have important ethical and practical implications for the patient’s standard of care and quality of life.23

Taylor raises an interesting question:

Will health care facilities be required to provide brain-scanning equipment under American disability law? ... Ultimately, if the appropriate legal framework develops, brain-scanning technology could
permit patients in vegetative states to make decisions regarding their own medical care and allow families to communicate with their loved ones.²⁴

Obviously, for practical and financial reasons, only selected major hospitals would be required to provide this service.

In a valuable article, Coleman and Pickard make these points:

Indeed, visual discrimination, speech comprehension and even the ability to respond to command have been demonstrated in some patients who are assumed to be vegetative on the basis of standard behavioural assessments. Functional neuroimaging is now increasingly considered to be a very useful and necessary addition to the clinical assessment process, where there is concern about the accuracy of the diagnosis and the possibility that residual cognitive function may have remained undetected.²⁵

A Christian Perspective

Prof. Francis Moloney laments that 'the theological commitment of Christianity to a life which extends beyond the limitations of this life is seldom heard in contemporary health care discussions'.²⁶ In truth, the Christian faith offers hope for believers and strength in the midst of present anxieties, fears and sufferings. They believe afflictions, sickness and death will eventually be overcome by our resurrection, guaranteed by Christ, who triumphed over death for humanity.²⁷ This is why death and suffering, though tragic, are not absolute evils for Christians.

The Catholic Position on the Ethical Duty to Provide Assisted Nutrition and Hydration (ANH) to PVS Patients, and Its Limits

On 20 March 2004 Pope John Paul II gave an address in which he stressed that patients in PVS were human beings with personal dignity and a moral right to 'basic health care'.

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 as long as it is seen to achieve its proper purpose, which in the present case consists in providing nourishment to the patient and alleviation of his suffering....

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.²⁸

Considerations for Moral Decision Making on ANH

- Each form of ANH has its risks to the health, or safety of patients: misplacement, serious infections, dislodgement of the tube and aspiration of food in tracts with a blockage.
- ANH is complex and may require light anaesthesia for insertion by a percutaneous endoscopic gastrostomy (PEG) tube.
- ANH's complications include diarrhoea, constipation and metabolic problems.
- Decisions on initiating, withholding, continuing or withdrawing ANH should be made on an individual basis after due clinical assessment.
- If doubts arise about pain or suffering being experienced, permanently unconscious or minimally conscious patients should receive palliative care, including appropriate analgesics.

In the Catholic tradition, a competent patient, with reasonable grounds, may morally refuse to have a tube inserted for the purpose of initiating life-prolonging ANH. Often a patient is seen as a person with a disease when in reality the patient is better viewed as a sick person.

Some ill patients may not want ANH simply because they lack an appetite for food, or because they find it too burdensome, physically or psychologically, without any suggestion of a suicidal intention. Failure to accept these factors would show a lack of respect for the dying person awaiting the onset of death. It would be ethical for competent patients, distressed by the thought of ANH continuing after they have been diagnosed to be in an irreversible unconscious state, to decide in advance to have ANH withdrawn if they fall into an irreversible

unconscious state. The reason is they believe being kept alive by ANH for a long time would be personally and ethically repugnant.

Pope Benedict XVI wrote: 'it is true that to eliminate death or to postpone it more or less indefinitely would place the earth and humanity in an impossible situation and even for the individual would bring no benefit.'

The Meaning of Good

John Paul, in his 1993 encyclical letter, Veritatis Splendor, clarified that the truly good determines the moral law and not vice versa:

Acting is morally good when the choices of freedom are in conformity with a human being's true good and thus express the voluntary ordering of the person towards his ultimate end: God himself, the supreme good in whom a human being finds his full and perfect happiness.

Speaking of the moral act John Paul adds: 'An act is therefore good if its object is in conformity with the good of the person with respect for the goods morally relevant for him.' He also says that 'an intention is good when it has as its aim the true good of the person in view of his ultimate end.'

The direct killing of permanently unconscious patients cannot be justified. In practice the benefit of any doubt should favour the view that there is an ethical duty to continue sustaining the lives of permanently unconscious patients by ANH unless it can be proved that this would not benefit them. If it is possible to communicate with PVS patients, that question should be put to them. If it is found that providing them with ANH is well received and they would like it to continue, then there should be done out of respect for them as human beings. If it is found that providing them with ANH results in prolonging their agony, this would raise serious ethical problems, which John Paul has already answered above.

In major hospitals, when communication with PVS patients becomes available and their responses indicate that ANH is prolonging lives of agony and they request ANH to cease, it would be ethical for doctors or nurses to comply with this request after an adequate warning has been given to them. On the other

Pope John Paul II was satisfied with moral certainty for the declaration of brain death of a person: 'a health-worker professionally responsible for ascertaining death can use these criteria in each individual case as the basis for arriving at that degree of assurance in ethical judgement which moral teaching describes as "moral certainty"'. This moral certainty is considered the necessary and sufficient basis for an ethically correct course of action. See also the 'Address of the Holy Father John Paul II to the 18th International Congress of the Transplantation Society', 29 August 2000, http://w2.vatican.va/content/john-paul-ii/en/speeches/2000/jul-
speech/documents/w2-jp-ii_spe_20000829_transplants.html.

Pope Benedict XVI, Sper Salvi, 'On Christian Hope', 11, my emphasis.

Pope John Paul II, Veritatis Splendor, 72.

Ibid., 78.

Ibid., 82.

30. John Paul was satisfied with moral certainty for brain death of a person, 'for the removal of organs in transplant cases'. See his Address to the Transplantation Society.