

Vegetative and Minimally Conscious States



Medical advances mean that increasing numbers of people survive trauma, stroke, periods of low oxygenation and severe brain infections. Some, however, are left with substantially reduced consciousness for months to years. This paper discusses the medical, legal and ethical challenges associated with the care of patients in vegetative and minimally conscious states.

Defining disorders of consciousness

Consciousness is the state of being aware of and responsive to one's surroundings. Disorders of consciousness include coma, the vegetative state (VS) and the minimally conscious state (MCS) detailed in Box 1. Patients can transition from one to the other and on to normal consciousness, or may remain in one state for a prolonged period of time.

- Coma is a state in which a person cannot be awakened and does not respond to any stimulation (including pain). Patients in a coma lack a normal sleep-wake cycle. Coma is not usually prolonged and not covered here.
- The **vegetative state (VS)** is wakefulness without awareness. Patients have a sleep-wake cycle and may respond to stimulation with reflex and spontaneous behaviours, such as grasping and grimacing. However, there is no environmental awareness or purposeful movement.
- The **minimally conscious state (MCS)** is wakefulness with minimal awareness. There is a broad spectrum of responsiveness within this umbrella term, ranging from patients who make a few non-reflex movements, to those

Overview

- A prolonged disorder of consciousness (PDoC) refers to a state where a patient has wakefulness but absent or reduced awareness for more than 4 weeks. The term encompasses both the 'vegetative state' (no awareness) and the 'minimally conscious state' (reduced awareness).
- The number of patients with such conditions is unknown; a national registry has been proposed to create an evidence base on prognosis.¹
- Clinical tools to improve diagnostic accuracy have been developed; research continues into the complementary use of functional MRI and EEG to evaluate consciousness.
- Commissioning and co-ordinating care for patients with PDoC is under review.
- The withdrawal of clinically assisted nutrition and hydration continues to provoke ethical and legal debate.

who smile, cry or laugh in response to emotional stimuli, verbalise, or use objects (e.g. a hairbrush) in a consistent, meaningful manner. The clinical criteria defining the MCS were published in 2002.²

In 2014 the Royal College of Physicians (RCP) published National Clinical Guidelines (endorsed by multiple stakeholders) addressing the issues.¹ This POSTnote focuses on the challenges associated with adult patients with disorders of consciousness for prolonged periods (see Box 1). These include: accurate diagnosis and prognosis in the absence of objective clinical tools or statistics, difficulties with commissioning and providing appropriate care, and debates on withdrawing and withholding treatment.

Because PDoC can result from numerous initial diagnoses, there are no reliable statistics on incidence or prevalence. Estimates (based on numbers of patients with PDoC in nursing homes in the UK) range from 4,000-16,000 patients in VS, with three times as many in MCS. The RCP guidelines suggest that a registry of long-term follow up data is needed in order to understand and communicate prognosis and the benefit of interventions better, as well as to direct funding more effectively.

Box 1. Prolonged and permanent disorders of consciousness

- **Prolonged: VS** and **MCS** are said to be prolonged when they have lasted for more than four weeks. Patients can remain in such conditions for many years, or even decades.
- **Permanent: VS** is said to be permanent when it has persisted for more than a year after traumatic brain injury or more than six months after other brain injuries. After these times, recovery from this state is considered to be highly improbable (< 1%).¹ The use of the term 'persistent' vegetative state is no longer recommended. **MCS** is more difficult to define, but the RCP guidelines state that a "a patient remaining in MCS for five years who is not showing improved responsiveness" is unlikely to recover.

Conditions that are not disorders of consciousness

- **Locked-in syndrome:** the patient is conscious, but paralysed.
- **Brainstem death:** there is a loss of all consciousness and brainstem functions including spontaneous breathing. A ventilator can be used to maintain the body to allow organs to be donated, but the patient is considered medically and legally to be dead.³

Diagnosis and prognosis**Clinical assessment**

The mainstay of diagnosing VS and MCS is evaluation by specialist doctors and other health professionals. They observe patients for behaviours that suggest awareness of self or of their environment. Accurate diagnosis is difficult for several reasons:

- patients often have accompanying mental or physical disabilities that may limit their ability to respond⁴
- patients are often assessed when still medically unstable⁵ and their conditions frequently change¹
- patients' responses are often delayed or inconsistent^{6,7}
- there is a degree of subjectivity in clinical observations.

Given these factors, misdiagnosis is common with up to 43% of patients initially thought to be in VS subsequently found to be in MCS.^{8,9} Several assessment tools have been developed and validated to improve diagnostic accuracy.¹⁰ Three are in common use in the UK.¹¹⁻¹⁴ These tools, while different in detail, have several common characteristics: they require assessment by a multidisciplinary team (ideally carried out in specialist centres), they require repeat assessments, at different times, and involve stimulation of different senses. Assessments are best when they involve the family and care team whose knowledge of the patient can be helpful.

Research into using technology to aid diagnosis

Because of the difficulties in making a clinical diagnosis, researchers are exploring how existing technologies might aid diagnosis (Box 2). These include functional magnetic resonance imaging (fMRI) where patients' responsiveness to certain stimuli can be assessed, or where they are asked to imagine tasks while in a scanner; electroencephalography (EEG) where brain activity is recorded using electrodes placed on the scalp, either at rest or in response to stimulus; and diffusion tensor imaging (DTI) where the brain's structural integrity is examined closely.

Re-evaluation

Experts agree that re-evaluation should occur at regular intervals (6 and 12 months, and yearly thereafter),¹⁵ to

Box 2. Investigations to aid diagnosis and prognosis

Currently, there is insufficient evidence for the following tests to be introduced into routine clinical practice. Most are undertaken in a research context and specialist expertise is required to conduct tests and interpret the results. Most of the studies occur at a single time, despite patients' alertness varying considerably over time. Using different techniques in combination or at different time periods could augment clinical evaluation leading to more accurate diagnosis and prognosis; further research with larger trials is needed.¹

Functional MRI (fMRI)

Researchers have assessed the use of fMRI in several ways. There is a close relationship between the level of response to sound stimuli and the patients' recovery at 6 months suggesting that this might be a helpful prognostic tool.²⁰ Other studies have revealed that a small proportion of patients thought to be in the vegetative state retain the ability to modulate willfully their brain activity, by performing mental imagery (for example imagining playing a game of tennis).²¹⁻²³ One patient was able to use this kind of directed attention to communicate correct answers to several yes/no questions.²⁴ Despite this presenting an important advance in the ability to detect what is termed 'covert cognition' (a hidden awareness of self and the environment) it cannot be used widely yet, as:

- there are many 'false negatives' with around one in five volunteers with normal cognition unable to generate fMRI activity
- few patients (less than 15%) tested show covert cognition.¹ It is not known whether the other 85% truly lack cognition, or the patient's brain arousal (at that particular time) is low, or whether they are one of the 'false negatives'
- many patients are not able physically to undergo an MRI because they are unable to lie flat, have frequent spontaneous movements, or have metal structures in their head.

EEG

EEG overcomes many logistical problems associated with fMRI, is less expensive, and can detect covert cognition in a similar way to that described for fMRI.²⁵⁻²⁷ Looking at whether patients experience the normal sleep-wake cycle in brain activity was found to be a reliable discriminator between VS and MCS in a study of 11 patients.²⁸

Diffusion tensor imaging (DTI)

This specialised MRI technique maps the nerve fibres in the brain. In established PDoC, it has shown differences in brain architecture, between VS or MCS in 25 patients;²⁹ it can also differentiate the cause of DoC (brain trauma or cardiac arrest).³⁰ DTI may help predict which patients with severe brain injuries will remain in VS.^{31,32}

detect any changes in patients' awareness, and such evaluation needs to occur when the patient is physically well. Following the publication of the RCP guidelines in 2014¹ patients newly diagnosed with VS or MCS are more likely to get such re-evaluations. However, there are an unknown number of patients in nursing homes or cared for in the community who have not been formally re-evaluated since their initial diagnosis. Without re-evaluation, transition from VS to MCS may go unrecognised. Regularly updating the diagnosis is critical to determine prognosis,¹⁵⁻¹⁹ direct appropriate rehabilitation and funding for continuing and/or social care, and for decisions about withdrawal of treatment.

Treatment

There are numerous medical and surgical interventions for an initial brain injury, and it is recommended that patients in VS or MCS are assessed in a specialist unit to identify and treat reversible causes.³³ Once a patient has been treated for the initial brain injury or event, and VS or MCS is

established, effective interventions are limited to specialist rehabilitation and care aimed at preventing complications.

Rehabilitation

The RCP Guidelines recommend that patients with PDoC should be treated in specialist rehabilitation centres, and notes that there are insufficient beds to meet demand.^{1,33} Patients should be moved after 3-4 months for 'slow stream' less intensive rehabilitation either in a specialised nursing home or, less commonly, their own home with specialised PDoC outreach support. Because patients can move from VS to MCS at different times, and their rehabilitation needs change, regular re-evaluation is required. There is concern from the relatives' support group 'Brain injury is BIG'³⁴, echoed by some clinicians,³⁵ that decisions about diagnosis and rehabilitation are made too early, and while patients are still physiologically not well. Incorrect diagnosis can have negative effects on the care, rehabilitation and funding patients receive.

Supportive Care for PDoC Patients

Patients are prone to develop significant complications. These can be acute and reversible (such as some kinds of pneumonias), or chronic and less reversible (such as contractures, where muscles shorten because they have been tight for too long). To prevent or limit complications, 24-hour care involving a range of specialities is required, whether the patient is in an acute or long-term setting. Expertise can include: nutritional support, chest physiotherapy, management of surgical airways (tracheostomies), physio- and occupational therapy to maintain tone and avoid contractures and the provision of specialised equipment such as seating supports.¹ Sitting in a wheelchair helps increase patients' levels of arousal and potential to interact.³⁶ Supportive care includes specialist assessments of whether patients may be suffering from pain or depression, about which they cannot communicate.³⁷⁻⁴³

Research into Other Treatments

There is no evidence that any interventions improve long-term outcomes (Box 3). Research into novel treatments is difficult. No animal model exists where meaningful changes in consciousness can be assessed, and PDoC patients by definition cannot consent to a trial: interventions that are invasive or where the risks are unknown give rise to significant ethical concerns, although legal representatives can consent for some trials. Long-term outcome data for standard interventions are thus valuable.¹

Providing and paying for care

The cost of treating patients with PDoC

While the initial costs of treating and rehabilitating patients with PDoC are unknown, estimates suggest that it costs around £7,500 a month to look after a patient in a permanent vegetative state.⁴⁴ Costs for MCS are likely to be similar, although individual patient expenditure will vary.

Commissioning and Co-ordinating Care

Integrating funding and care for patients with PDoC is

Box 3. Treatments being researched

'Sensory stimulation', such as listening to music or receiving massage has not been proven to change the level of awareness⁴⁵ but is unlikely to do any harm so long as stimuli are provided one at a time, and for short periods.⁴⁶ Direct electrical⁴⁷ or magnetic⁴⁸ brain stimulation has been associated with modest gains in motor and verbal function in about 20% of patients.⁴⁹ The neurostimulant drug amantadine has been associated with a faster initial speed of recovery, but the long term outcomes are not yet known.⁵⁰ A randomised controlled trial has not yet been conducted. There have been reports of the sedative drug zolpidem causing arousal⁵¹⁻⁵³ in PDoC patients, but the effects are short lived. It could potentially be used as a 'screening' drug to identify patients who may respond more to other interventions.⁵⁴

challenging, particularly as their requirements change.⁵⁵ In England, the first 3-4 months of care is usually commissioned (paid for) by NHS England, with further care being provided by local Clinical Commissioning Groups (CCG). There are problems with this model. Patients' needs for specialist services may last longer than this, or come later. In addition, conflicts of interest can exist in terms of paying for and supplying long-term care; for example there are disincentives for organising specialist equipment such as chairs, as another commissioning body will bear the cost if it is done later. There are discrepancies in what will be provided if a patient receives their funding either through medical or social funding streams. The RCP guidelines recommend that national specialist commissioning should fund all active healthcare and that all long-term care costs in specialist nursing homes or elsewhere should be funded as continuing healthcare.¹ Other commissioning models, including the 'year of care'⁵⁶ are being considered.⁵⁷

Withholding and withdrawing treatment

Decisions about when to give, withhold or end treatment are guided by the patient's wishes (if known), professional ethics and codes of practice, and pertinent legislation and case law, described below. In the UK, a patient with the capacity⁵⁸ to make the relevant decision has the right to refuse but not to demand treatment,⁵⁹ to treat a patient against their will is considered assault⁶⁰ and to give a patient a treatment where the risks outweigh the benefits is malpractice.⁶¹ The challenge is how to apply these principles to patients who lack capacity to refuse treatment, and about whom there often remains uncertainty about diagnosis, prognosis, and the benefits of various treatments. Very few patients (under 4%)⁶² have documented their treatment preferences in any advance statement, a binding advance decision to refuse treatment (see POSTnote 481)⁶³, or appointed a lasting power of attorney. The Mental Capacity Act (MCA)^{58,64} instructs that in these circumstances doctors must act in the patient's 'best interests' which incorporate not only medical interests but 'the patient's welfare in the widest sense'.⁶⁵ A recent judgment in the Supreme Court (*Aintree vs James*)⁶⁵ emphasised that the focus should be on whether it is in the patient's best interests and therefore lawful to continue to *give* rather than *withdraw* certain treatments.

A European survey reported that the majority of people would not want not be kept alive in a vegetative or minimally

conscious state.^{66,67} Enquiries to ‘Compassion in Dying’⁶⁸ (a charity that provides information and support around end of life rights and choices) doubled after media stories about patients in MCS were published.⁶⁹ However, the difficulty of predicting what one would want in a future altered state is well documented.⁷⁰ An individual may think they would not want to live with a profound disability, but find that it is not as limiting as they had imagined, or change their mind.⁷¹ Family members may believe in much more positive outcomes than are likely⁷² and most fight for continued treatment in the early years. Over time, some feel that their relative has recovered sufficiently to gain pleasure from some activities and that ongoing treatment is justified. Others believe that their relative would not have wanted to survive in their condition.⁷³ Rarely, some have attempted to end the patient’s life.⁷⁴ Interviews with family members on the website ‘healthtalk’ highlight these issues.⁷²

Withdrawing clinically assisted nutrition and hydration (CANH)

Treatments to support or prolong life, such as ventilation, dialysis, or cardiopulmonary resuscitation are often withheld or withdrawn when the clinicians and family are in agreement that the patient would not benefit from them.^{75,76} However, the practice of obtaining judicial approval for the withdrawal of CANH in all persistent vegetative state (PVS) cases (see Box 4) is obligatory and formalised through the Code of Practice issued under the MCA.^{76,77} One of the reasons that CANH is treated differently from withdrawal of other treatments is that the mode of dying is very different, particularly in a brain-damaged patient whose body is in good health and well nourished: the death can be protracted (up to three weeks); it is sometimes associated with physiological responses that are unpleasant for carers or loved ones to witness (such as grimacing, sweating and involuntary movements); and it renders the organs unsuitable for donation, which can compound a family’s distress. In addition to the c.100 cases of patients in VS who have been the subject of judicial applications, two recent cases of patients in MCS have also been heard. In the first (*W vs M*)⁷⁸ the family stated that M would not have wanted to exist in her state, but the judge found that, since clinical staff reported she gained pleasure from some things, withdrawal was not ‘in her best interests’. This prompted significant ethical and legal debate.⁷⁹⁻⁸⁴ In a recent case a tube to deliver artificial nutrition was not replaced in a patient with MCS: the judge ruled that the physical and psychological risks of continuing CANH outweighed the benefits.⁸⁵

Applying to the Court of Protection (CoP)

The Court of Protection is a specialist court (created in 2007) for people who lack capacity to make specific decisions for themselves. Going to the Court of Protection using standard processes incurs significant cost and delays in decision-making, even in cases of patients in PVS where the family, doctors and lawyers are in agreement that withdrawal is in the patient’s best interests.⁴⁴ One solution might be to require only written (rather than written and oral)

Box 4. The case of Tony Bland

The first case of a disorder of consciousness heard in court was that of Tony Bland, who suffered brain damage in the Hillsborough disaster (1989) through lack of oxygen, and was diagnosed as being in a vegetative state. In 1992, the House of Lords ruled that it was no longer in Mr Bland’s best interests to receive clinically assisted nutrition and hydration and therefore no longer lawful to provide it.⁸⁷ They emphasised that all similar cases should go to the court “...until a body of experience and practice has been built up which might obviate the need for application in every case”. Around 100 cases of patients in a vegetative state have been heard in court since then.

submissions in cases of patients with PVS where the family, doctors and lawyers are in agreement that withdrawal is in the patient’s best interests.⁸⁶

It is unclear who is responsible for applying to the Court and when such an application should be made. In the past, families (rather than the NHS) have often had the responsibility for the applications and have thus been faced with the burdens of timing of decision-making, legal costs (at least £30,000⁴⁴) and media attention. Other families have not known that such applications were possible. To counter these problems, the RCP guidelines suggest that funding a court application should be the responsibility of the service commissioners.¹ They also recommend that ‘best interest’ meetings between clinical teams and families (or an independent advocate) should be held routinely, four weeks after the diagnosis of permanent VS. These meetings initiate conversations to establish what the patient’s wishes might have been in these circumstances, and which treatments (from antibiotics to CANH) are in the patient’s best interests.¹ While there is agreement that ‘best interest’ meetings should be held routinely, concerns have been expressed³⁴ that four weeks post diagnosis of PVS may be too early. Well-publicised (but sometimes misdiagnosed/misreported) cases of unexpected recovery to states of full or partial consciousness^{88,89} may influence relatives’ receptiveness.

Beyond the withdrawal of treatment

Arguments have been made that, if a court is prepared to authorise withdrawal of CANH (following which death is inevitable), it should also be able to authorise terminal sedation, which would allow a predictable time of death (with family present if desired), fewer manifestations of physiological distress, and organ donation.⁹⁰ The opposing argument centres around the difference between withdrawing a life-preserving treatment that does not benefit the patient, and deliberately ending life by an act.^{91,92} Groups opposed to euthanasia in any context emphasise that what is needed is early involvement of specialist palliative care to control physiological symptoms during dying.^{1,93} Current guidelines suggest that this should ideally be carried out in a specialised centre, while others consider specialist palliative care input at the patient’s home would be sufficient, and allow family members to be close.⁹⁴

Endnotes

See overleaf.

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