



Coma and Disorders of Consciousness
research centre

The 'window of opportunity' for death after severe brain injury: Family experiences

EXECUTIVE SUMMARY

Purpose of this document:

This document provides a summary of key issues confronting relatives of severely brain injured patients (e.g. in a vegetative or minimally conscious state) when they believe that their relative would rather not be kept alive in their current condition. It presents new evidence from these families about the practical, legal, social and ethical challenges they face in the UK medico-legal context. It makes recommendations about planning for end-of-life and improving decision-making options and processes.

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Target Audience:

This summary is intended for legal and health care policy makers and practitioners involved in delivering services to severely brain-injured patients and their families (from intensive care to long-term care home settings). We hope that it will promote public debate and provide evidence to inform legal and policy decisions and changes in practice.

Acknowledgments:

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The Coma and Disorders of Consciousness Research Centre is pursuing interdisciplinary work focusing on the experiences of families with a severely brain-injured relative, drawing on our data set of now more than 65 interviews.

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www.cdoc.org.uk

What is already known?

The concept of the 'window of opportunity' is widely used in medicine to denote a critical time period during which providing an intervention may help achieve a desired outcome and where delay may mean that the opportunity is lost forever.

Recently the concept has been extended to refer to the time-limited period when withdrawing (or withholding) medical interventions can achieve the desired outcome of allowing a patient to die when continued survival merely prolongs dying, increases suffering, and/or runs counter to the patient's wishes.

The 'opportunity' for death is particularly pertinent to severely brain injured patients as the ability of medicine to save or restore the body has outstripped its ability to save/restore the brain – and survey research shows that most people report that they would not want to be kept alive in long-term vegetative or minimally conscious states.

However, the early prediction of long-term neurological outcome after severe brain-injury is difficult and uncertain. A firm diagnosis of 'permanent vegetative state' is possible only after several months (anoxic injury) or a year (traumatic injury). By the time a firm diagnosis is reached the 'window of opportunity' for death may have considerably narrowed. This is because patients often stabilise over time - at which point the only life-sustaining treatment essential to on-going survival is artificial nutrition and hydration.

There is a dilemma for patients, clinicians and families. The 'window' for death for severely brain-injured patients may be open early on after injury - when the prognosis is most uncertain and the person might want to be given the opportunity to recover consciousness to see whether a quality of life acceptable to them can be achieved. The 'opportunity' to die may close later when there is physiological recovery, alongside more certain prediction of the likely extent of the person's long-term level of impairment.

Some patients are then left subject to life-sustaining treatment that they might have refused. Conversely, some clinicians (who are well aware of the closing 'window') may be letting patients die (while the 'window' is still open) when those patients might have recovered to a quality of life they would have wanted.

In the UK clinicians cannot legally withdraw artificial nutrition and hydration from vegetative or minimally conscious patients without recourse to the courts. Such applications are rare (only around 100 cases) and, so far, ANH withdrawal has only once been approved for a patient diagnosed as 'minimally conscious'.

What our research adds:

Our research is the first to report on the experience of families of severely brain-injured patients in relation to the dilemmas created by the medico-legal ‘window of opportunity’ for death.

This article focuses on those of our interviewees who believed that their relative would not have wanted to be kept alive in their current condition (vegetative, minimally conscious or with profound neurological deficits). Interviewees made comments such as: *‘The ones that don’t survive are the lucky ones’*. Some families with relatives who had emerged from vegetative into minimally conscious states viewed this as even worse – because the patient now appeared to have some awareness of their situation: *‘as he wakes up he grimaces and roars. He is very aware of his situation, and his situation isn’t one you’d want to be aware of’*.

None of the patients had a valid and applicable Advance Decision in place to refuse treatment (and none had previously appointed anyone with Lasting Power of Attorney to make health decisions on their behalf). Decision-making was therefore the responsibility of their treating clinicians. These clinicians were duty bound to act in the patient’s ‘best interests’ – which includes, but is not determined by, the patient’s prior expressed values and beliefs.

A minority of interviewees believed that their relative would have refused life-sustaining treatment very early on (even if the prognosis was not certain). Their request for treatment withdrawal/withholding on that basis had been over-ruled by doctors, and some interviewees reported evasion or even hostility from staff when they tried to discuss non-treatment options. Some interviewees felt that they were sidelined in decision-making and that their relative’s own values were not entered into the decision-making process.

However, most interviewees felt their relative *would* have wanted treatment in the early period because they would want to be kept alive until the prognosis became clearer. Some interviewees had even initially fought for treatment to be given against the advice of clinical teams. Regret with the benefit of hindsight was common. As one mother commented: *‘Would that they hadn’t got to Charlie in time to resuscitate him - knowing now what I didn’t know then’*.

By the time families were talking to us, ‘ceilings of care’ had been put in place for all patients with the agreement of our interviewees e.g. no cardio-pulmonary resuscitation, no aggressive treatment with antibiotics. However:

- ‘Do Not Attempt Resuscitation’ decisions were viewed as ‘too late’ (to allow death) by some families, since the patient had already been repeatedly resuscitated and there was little prospect that cardio-pulmonary resuscitation would be needed in the future.
- Although decisions to withhold treatment had been made these did not always allow for the hoped for ‘release’ (e.g. patients had recovered from pneumonia even without aggressive antibiotics).
- Best interests decisions were not always followed in practice. This was either because a family member intervened in reaction to perceived suffering (e.g. after witnessing their relative choking with pneumonia, apparently without provision of adequate palliative care); or because doctors or care homes acted apparently without reference to previously agreed decisions and without a best interests review (e.g. transferring a PVS patient to hospital to be placed on a ventilator).

The withdrawal of artificial nutrition and hydration had not been seriously considered for most of these patients. Although current law suggest that clinicians should consider withdrawing ANH for patients with a confirmed PVS diagnosis this had not been raised with every relevant family in our sample. Interviewees reported that they were reluctant to initiate such discussions themselves because they were intimidated by the thought of court proceedings and, as one commented, *‘I’d feel like a monster suggesting that’*. Most viewed the withdrawal of ANH as ‘cruel’ or ‘barbaric’ and thought that active euthanasia would be kinder than letting their relative (as they saw it) ‘starve and dehydrate’ to death. These families felt in limbo and many did not know what the options were, or even who was responsible for decisions and/or felt there was no acceptable option left.

Recommendation 1

This research underlines the need for public information including:

- Encouraging discussion among friends and families about wishes in relation to end-of-life issues, alongside a public education initiative to let people know that ‘next of kin’ have no right to refuse treatments on their relatives’ behalf and that ‘pulling the plug’ is not a straightforward option (legally or clinically) for most patients in vegetative or minimally conscious states.
- Providing information about ‘Living Wills’ – legally binding Advance Decisions to refuse treatment, which may allow a person’s prior expressed wishes to be honoured.

Recommendation 2

This research underlines the need for high-quality decision-making including:

- High quality care and diagnosis to ensure the best possible *clinical* information informs best interests decision-making at every stage.
- High quality processes for learning about the patient’s prior values and beliefs to ensure that the best possible knowledge about *the individual* informs best interests decision-making at every stage.
- Information and support for family/friends to help them provide appropriate input – including clear guidance about their role in best interests decision-making and information about the ‘window of opportunity’ dilemma created by the current medico-legal framework.
- Properly conducted, documented and communicated ‘best interests’ meetings (in accordance with the Mental Capacity Act 2005) and rigorous compliance with best interest procedures (e.g. the appointment

of an Independent Mental Capacity Advocate if the family are considered inappropriate to consult).

- Regular patient reviews - with clinicians taking responsibility for raising questions about treatment withdrawal.

Recommendation 3

This research underlines the need to ensure good palliative care and suggests a need to revisit questions about the withdrawal of artificial nutrition and hydration (ANH). We recommend that:

- Withholding/withdrawing of any life-sustaining treatments must be accompanied by good palliative care for the patient, and by good information and support for both families and staff.
- Withdrawing or withholding of ANH should either not require an application to the Court of Protection (e.g. where there is a firm diagnosis and consensus); or such applications should be streamlined so that families do not feel intimidated and delays are minimised.
- There is a need to broaden the so-called ‘right to die’ debate beyond the terminally ill and those with full mental capacity. This problem of the ‘window of opportunity’ for death for severely brain-injured patients could be resolved if euthanasia were made available to them because as Cochrane (2009) argues: ‘if it were just as easy to “pull the plug” later, most patients would undoubtedly wait for more prognostic certainty’. We recommend serious discussion about the impact of current legislation and social policy on euthanasia on the lives and deaths of vegetative and minimally conscious patients (and the impact of this on their families), including serious consideration of what can be learnt from other countries.

For more information about the ongoing work of
the Coma and Disorders of Consciousness Research Centre see:
www.cdoc.org.uk