

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

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Abstract This article builds on and develops the emerging bioethics literature on the 'window of opportunity' for allowing death by withholding or withdrawing treatment. Our findings are drawn from in-depth interviews with 26 people (from 14 different families) with severely brain injured relatives. These interviews were specifically selected from a larger study on the basis of interviewees' reports that their relatives would not have wanted to be kept alive in their current condition (e.g. in vegetative or minimally conscious states). Our analysis tracks the decision-making processes that have led to the situation in which life-sustaining treatments continue to be delivered to these patients – maintaining them in a state that some families describe as a 'fate worse than death'. We show how the medico-legal 'window of opportunity' for allowing the patient to die structures family experience and fails to deliver optimal outcomes for patients. We end with some suggestions for change.

Keywords: brain injury, death, window of opportunity, ethics, vegetative, minimally conscious

Introduction

The concept of a 'window of opportunity' is widely used in medical and health-related research to denote a critical period during which an intervention will be maximally beneficial in achieving a desired outcome and where delay may mean that the opportunity is lost forever. Medical literature on trauma patients commonly refers to a 'golden hour' and 'silver day' after injury, both formulations designed to capture the notion that morbidity and mortality are disproportionately affected if treatment is not provided promptly (Lerner *et al.* 2001). Depending on the intervention under consideration, the 'window of opportunity' can range from merely hours (e.g. the protective effect of one particular treatment for stroke patients is completely lost eight hours post injury, Markgraff *et al.* 1998) through several months, or even years (e.g. education to prevent Hepatitis C needs to be within three years of onset of IV drug use, after which users are normally already infected, Grebely and Dore 2011).

Recent clinical and ethical discussion extends the concept of the 'window of opportunity' 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

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prolongs dying, increases suffering, and/or runs counter to the patient's wishes (Fisher and Ridley 2012). In this context clinicians are cautioned against 'life-sustaining treatment by default' (Braun and McCullough 2011) and are bound by contemporary standards of medical ethics not to carry out life-sustaining but non-restorative treatments when these carry a substantial risk of an outcome that the patient would find unacceptably bad (Crippen 2005). The concept of the 'window of opportunity' as an opportunity to withdraw or withhold treatment has been applied particularly in bioethical research on end-of-life decision making for adult stroke victims (Cochrane 2009), for infants with birth asphyxia (Kon 2009, Wilkinson 2009), and for patients with severe brain injury (Wilkinson 2011). The research reported here extends and develops work in this area with empirical data on a previously unexplored area: family experiences of the 'window of opportunity' for allowing death for a severely brain injured family member.

Severe brain injuries can come without warning and affect previously completely healthy adults and young people. The usual causes are external trauma (e.g. from road traffic accidents, falls, and assaults, Kraus and McArthur 2006: 7) or events that deprive the brain of oxygen (e.g. cardiac arrests). They can also result from illness that directly attacks the brain (e.g. viral encephalitis). Late twentieth and early twenty-first century developments in medical technologies (e.g. resuscitation techniques, surgical procedures, the design and availability of artificial ventilation, and the delivery of artificial hydration and nutrition) mean that, in Europe and the US, increasing numbers of people are now being kept alive after very severe brain injuries which have left them in a 'persistent vegetative' or 'minimally conscious' state. The 'persistent vegetative' state is a diagnostic category first created in the early 1970s to describe a deep and sustained form of unconsciousness (Jennett and Plum 1972). The 'minimally conscious state' [MCS] is a more recent diagnostic category used to describe patients who demonstrate some discernible minimal and intermittent evidence of consciousness (Giacino *et al.* 2002). Patients who have been in a persistent vegetative state for a year (or earlier if the injury is anoxic) are highly unlikely ever to regain consciousness and are defined as being in a '*permanent*' vegetative state [PVS]. Similarly, those persisting in MCS may never regain consistent awareness. However patients can sometimes emerge into full consciousness after years or even decades in MCS (Fins *et al.* 2007). However, the longer the duration of the vegetative or minimally conscious state, the more profound the person's mental and physical impairments even when fully 'awake' (Katz *et al.* 2009). For example, severely brain injured patients can recover consciousness without regaining the ability to swallow properly, with extreme neuro-fatigue, compromised memory and limited ability to control their limbs and communicate or to make sense of the world around them. They are usually free of artificial ventilation, but are dependent on artificial nutrition and hydration and round-the-clock care.

Many people report that they would not wish to be kept alive in these states. For example, a European-wide survey of nearly two and a half thousand medical and paramedical professionals found that 82% would prefer not to be kept alive in a permanent vegetative state, and 70% would prefer not to be kept alive in a minimally conscious state (Demertzi *et al.* 2011, see also the Gallup poll of American views cited in Constable 2012: 160). Some commentators see survival after serious brain injury *with* some degree of consciousness as actually *worse* than survival in a PVS, since the person then has the capacity to experience pain and has some – albeit possibly fragmented and transitory – awareness of their situation (Ashwal and Cranford 2002).

Without the intervention of modern medicine, these patients would have died, but now the capacity to restore physical function (e.g. the beating heart and the breathing lungs) has outstripped medicine's ability to heal the brain. Many clinicians are, of course, very aware of

the problem of 'interrupting death' only to leave people trapped in a state that they would not want. Indeed, some neurosurgeons themselves, for this very reason, would refuse the life-sustaining interventions that they use on others unless there were much better odds of recovery to functional independence (Barlow and Teasdale 1986). The problem is that, once the injury has occurred, the person lacks capacity to make their own 'real time' decision about whether or not to accept life-sustaining treatments [LSTs]. Instead, a decision must be taken on their behalf. In the UK this decision must be made in the patient's 'best interests', and not simply on the basis of substituted judgment (as is the case in the USA – where the person's prior expressed wishes have greater weight). Final responsibility for withdrawing or withholding LSTs rests with medical consultants (supported by the clinical team): although family members should be consulted, they have no legal rights to give consent to, or to refuse, medical treatments. (The relevant statutes are the Mental Capacity Act 2005 for England and Wales and the Adults with Incapacity [Scotland] Act 2000 for Scotland.)

The dilemma for brain-injured patients (and their families and clinical teams) is that it is often difficult to predict long-term neurological outcome in the early days. There is no straightforward choice between death and recovery after severe brain injury, but instead a range of intermediate outcomes (PVS, MCS and profound neurological deficit) such that 'survival therefore is not necessarily equated with success and, to at least some observers, is not always preferable to death' (Barlow and Teasdale 1986: 990). The prognosis becomes much clearer with time, simply by waiting for patients to 'declare themselves' by showing signs that they are – or are not – recovering consciousness and cognitive function. However, at the same time, the 'window of opportunity' for many treatment withdrawal decisions closes as the patient no longer requires LSTs for survival.

For people with severe brain injury, the 'window of opportunity' for death begins with the precipitating incident – when they could, for example, die instead of being resuscitated after a cardiac arrest – and extends (usually for a few months at most) until the person is no longer dependent on interventions such as surgery, mechanical ventilation or a tracheostomy. A later window may also open up if the patient subsequently suffers a potentially life-threatening illness for which treatment could be withheld. The vast majority of severely brain-injured patients do, however, remain dependent on artificial nutrition and hydration [ANH] via a feeding tube into the stomach – the provision of which is clearly essential to the maintenance of life for patients who cannot swallow. Withdrawal of ANH from a patient in a permanent vegetative state [PVS] was given court approval for the first time (in England) in 1993 in the groundbreaking case of Tony Bland, who was brain injured in the Hillsborough disaster (*Airedale v Bland* [1993] 1 All ER 821, 828) but – unlike withdrawal in terminal cases – continues to require a court application. However, since *Bland*, ANH withdrawal has been pursued only for a tiny minority of patients diagnosed as PVS in England and Wales (about 50), and it has never been made available to patients diagnosed as minimally conscious. The only family so far to have brought a legal case for withdrawal of ANH for a patient diagnosed as MCS was refused permission (*Re M, W v M* (2011) EWHC 2443 (Fam)) and commentary on this case illustrates the extent to which ANH withdrawal in these circumstances poses a complex set of legal, ethical and diagnostic issues (Kitzinger and Kitzinger 2011, Gillon 2012, Heywood 2012, Sachdeva and Butler-Cole 2012, Sheather 2012). The possibility of authorised ANH withdrawal via the courts does mean, however, that – at least for some (PVS) patients – there remains an 'opportunity' for death whether or not the clinical team (or the family) wish to pursue this route.

We have not found any empirical research that addresses this issue of the 'window of opportunity' for death as it is experienced by the families of severely brain injured patients. Literature exploring the experiences of such families tends to focus on families' emotional

problems and coping responses (e.g. Marsh *et al.* 2002, Schonberger *et al.* 2010) rather than on their engagement with decision-making. Insofar as families are mentioned in the ‘window of opportunity’ literature, it is generally assumed that they demand that their family member should be kept alive at all costs – irrespective of diagnosis or prognosis – because they have unrealistic expectations for recovery and/or because, for them, life (however compromised) is always better than death (e.g. Fisher and Ridley 2012). In a rare (ethnographic) discussion of one family’s request to terminate LSTs for a patient with traumatic brain injury, Kaufman (2005: 305) comments that this request is ‘unusual’ and that ‘most families ask that everything be done to keep their comatose or severely ill relatives alive indefinitely’. For families who want their relatives kept alive, it is of course inappropriate to talk about the closing of a putative ‘window of opportunity’ for allowing death since they construe death as a threat to be averted rather than an opportunity to be grasped. Our focus here is on those families (like the one Kaufman describes, and like the families in *Bland* and *W v M* court cases) who believe that the patient would want to die rather than continue to exist in their current circumstances. For such families the patient’s death is a desired outcome which is circumscribed and curtailed by the limited ‘window of opportunity’ for treatment withdrawal.

Method

The research reported here is part of a larger ongoing in-depth interview study of the experiences of families with a severely brain-injured relative. Ethical approval for the study as a whole was obtained from the Universities of York and Cardiff ethics committees and interviews are conducted by the authors. We are recruiting research participants through advertising via brain-injury support groups and websites and through our own social contacts (we have a severely brain-injured sister), through contacts made after giving formal presentations about our research, and via snowball sampling. So far we have interviewed 34 people (from 21 different families). This recruitment method clearly does not result in a sample representative of all families with severely brain-injured members: no claims as to representativeness are made, and neither our findings nor the recommendations based on them depend upon a representative sample.

Twenty six of the interviewees (from fourteen families) within this broader study believe that their relative would rather be dead than maintained in their current situation. Such people are part of a hard-to-reach group: the (unknowable proportion of) families of severely brain injured people who want their severely brain injured loved one to die. These families’ voices are rarely represented either in clinical, bioethical or social science literatures (much of which focuses on families’ struggle to keep the patient alive and receiving high quality care, Fins 2010). We have analysed the data from these 26 interviewees here in order to shed light on family experiences of the ‘window of opportunity’ for death. We emphasise, for the avoidance of doubt, that we are not making statistical claims about the proportion of families nationally who take this position nor are we claiming that these families are necessarily correct about what their relative would want (although note that surveys regularly find that around three-quarters of people would not wish to be kept alive in PVS or MCS, Demertzi *et al.* 2011). Our criterion for including interviews in the sample analysed here was an explicit statement such as ‘[She] would’ve definitely have wanted to be dead’ (Mandy’s family, F11); ‘His existence is not what he wants’ (Nick’s family, F10); ‘if he was asked now in his current condition and if he could communicate, he would not want to be here. He would certainly not want to be kept alive with a tracheotomy tube and a feeding tube in his nose’ (Wayne’s family, F5). Although not a defining criterion for inclusion, it so happens that

in none of the fourteen families was there any family member who opposed the view that the person would rather be dead – although it was apparent that different family members had come to this conclusion at different times and with different degrees of conviction or ambivalence. It is also worth noting that five of these fourteen families had consulted lawyers in order to find out whether they could allow their loved one to die – although, at the time of interview, only one of these families had a relative who had remained in a vegetative state, the other four having regained some level of consciousness.

Interviewees were parents (n = 9), siblings (n = 5), spouses/partners (n = 5), adult children of the patient (n = 4) and other family members (n = 3). Further details about the patients are provided in Table 1. As indicated, the patients' ages ranged from teens to early seventies and the diagnosis as reported in interview ranged from PVS (n = 5) through possibly or definitely MCS (n = 5), to those who emerged from vegetative/minimally conscious state to survival with profound neurological deficit (n = 4).

Interviews were transcribed orthographically and care taken to maximise confidentiality by use of pseudonyms for people and places. We have also at times left particular quotations unattributed, changed the gender of a patient or speaker, and – very occasionally – changed significant identifying details (e.g. one of these families' relatives recently died from pneumonia but we have avoided making this apparent in our use of the data). In analysing the data we used thematic analysis to identify recurrent patterns (themes) following the procedure described in Braun and Clarke (2006). So, for example, in seeking to identify moments when the opportunity to die was taken or missed, we searched systematically for places where interviewees talked about medical interventions at critical periods (e.g. antibiotics for life-threatening pneumonia) and extracted interviewees' accounts about the

Table 1: *Patient Details*

<i>Family (see Note 1)</i>	<i>Patient's age at injury</i>	<i>Length of time since injury</i>	<i>Diagnosis (See Note 2)</i>
F1	30s	6yrs +	Permanent Vegetative State [PVS]
F2	30s	4yrs +	PVS
F3	70s	9yrs +	PVS
F4	Teens	9yrs +	PVS
F5	50s	< 1yr	PVS
F6	40s	3yrs +	PVS/MCS
F7	20s	3yrs +	PVS/MCS
F8	60s	4yrs +	PVS/MCS
F9	Teens	6yrs +	PVS/MCS
F10	20s	4yrs +	Minimally Conscious State [MCS]
F11	40s	2yrs +	Profound Neurological Deficit
F12	40s	4yrs +	Profound Neurological Deficit
F13	70s	1yr +	Profound Neurological Deficit
F14	50s	15 yrs +	Profound Neurological Deficit

Note 1: The family code number (F1 to F14) appears against each quote used in this article – except on a few occasions where, for example, family members in our sample were estranged from each other and did not want other relatives to know that they had also spoken to us.

Note 2: Except in two cases (where we saw legal reports including expert statements about diagnosis), we have relied on family members' accounts of the diagnosis assigned by medical professionals. Some families reported professional uncertainty or disagreement between professionals about the patient's diagnosis – in all cases relating to the PVS/MCS boundary (Families 6-9). (Note that the patient in Family 5 has an anoxic injury, hence the early diagnosis of permanent VS.)

decision-making process. Theoretically we treat the data in an essentially 'realist' tradition and understand what people say in interview as 'interpretative autobiography' (see Kitzinger and Willmott 2002).

Findings

All fourteen families arrived at the conclusion that their loved one would rather be dead by considering the medical situation as they understood it (including diagnosis and prognosis), in conjunction with their knowledge of their loved one's prior expressed values and beliefs, their understanding of that person's current experience (if any), and their family culture. For a few families this led to a very early (and united) view that their relative might not wish to have LSTs: in four families (F5, F11, F12, F14) interviewees reported having conveyed this 'substituted judgment' to doctors within the first week of the precipitating event. These families were unusual in our sample in that all of them had previously had detailed explicit discussions about their attitudes toward death, mental disability and risk (e.g. weighing the risk of premature death against the risk of surviving with severe impairment), and were aware of the problem of patients receiving unwanted treatment. In two cases the patient and their family had been previously involved in decision-making about life-sustaining treatment for other family members with severe brain injuries. However, in none of these families did the injured individual have a legally valid and applicable Advance Decision (or 'living will') which would have permitted them prospectively to refuse LSTs – and in all cases life-sustaining treatments were continued.

The other ten families took much longer to come to the position that their relative would rather be dead. Initially they accepted LSTs for their relative without challenge, and even sometimes actively pursued LSTs in the face of suggestions from clinicians that LSTs should be withheld or withdrawn. Family desire to pursue LSTs against the judgment of clinicians is well documented (e.g. Kaufman 2005) and the reasons our interviewees give for having been unwilling to accept withdrawal of LSTs map on to those previously discussed: not understanding the diagnosis or prognosis (or being misinformed about it); having unrealistic expectations for recovery; clinging to hope; being unwilling to 'let go'; or believing that it is up to the incapacitated person themselves to make the decision. Our interviewees often interpreted the fact that their relative had survived 'against the odds' as evidence that the patient would defy grim statistics about likely level of recovery. Many also believed that it was important to 'give her a chance', not to 'give up on her too soon' without realising that a 'window of opportunity' for death might swing shut and close down the exit option if the hoped-for level of recovery was not attained. Only when they believed the prognosis to be sufficiently certain, gave up hope in future recovery, and/or witnessed the extent of their relative's apparent suffering did they conclude that their relative was enduring a 'fate worse than death'.

In the following sub-sections we explore the series of key decisions implicated in the patients' survival in their current state. Our analysis of family reports reveals how the 'window of opportunity' for death may have been missed across five different key decision points: (i) Emergency and intensive care; (ii) Mechanical ventilation and/or tracheostomy; (iii) Resuscitation; (iv) Antibiotics; (v) Artificial nutrition and hydration.

Emergency and Intensive Care

In terms of allowing severely brain injured patients to die, the most effective time to withhold or withdraw medical interventions is either at the scene of the triggering event or in the

emergency room or intensive care unit fairly soon afterwards. Of those who survive traumatic brain injury long enough to enter hospital, around 40% die within days or weeks (Narayan *et al.* 2002) and decisions to withhold or withdraw treatment precede the majority of all deaths in emergency departments and in intensive care (Smedira *et al.* 1990, Ferrand *et al.* 2001, Sprung *et al.* 2003).

In our sample, emergency life-saving decisions were made (in most cases) before family members were on the scene. However, where family members *were* present they all supported intervention (e.g. attempting resuscitation). Most felt it is only with the benefit of hindsight that such decisions could be judged inappropriate. Tania's view now is: 'Would that they hadn't got to Charlie in time to resuscitate him – knowing *now* what I didn't know then' (F4). Similarly, Fiona's family now believe that resuscitating her and treating her repeated cardiac arrests in the ambulance and on arrival in hospital defied 'common sense'. Fiona's mother believes that her daughter drowned and 'did really die' at the accident site and Fiona's sister, Bea, agrees, adding 'we do find it stupid that they didn't leave it at that' (F1). Freida reflects on what happened to her mother and says: 'It's hard to say that the bloke [a doctor who was on the scene] should have let her bleed to death in front of him. You know, die – stop breathing and not revive her'; but adds, that when he subsequently came to see her mother: 'he burst into tears and he said: "I really hoped I was doing the right thing". I got the feeling that he realised he hadn't' (F15).

Some interviewees, however, report having raised contemporaneous concerns about LSTs in emergency care. For patients with traumatic brain injuries surgeons often advise operating to remove blood clots and/or to relieve brain pressure. The implications of such decisions in relation to the 'window of opportunity' are not straightforward in that, for example, while a failure to relieve brain pressure might allow the patient to die, it might alternatively simply lead to their survival with increased brain injury. Most family members were content for such operations to proceed but, even at this early stage, some expressed reservations. The Hawes family (F14) had some prior knowledge about brain injury and Barbara Hawes had expressed strong views about her own wishes in such situations. Although her family agreed to an emergency operation to remove blood clots, they had doubts about whether Barbara would want the decompressive craniectomy (to relieve brain swelling), proposed a few days later. Her husband reports saying to the surgeon 'let her die if you think the prognosis is bad'; her adult daughter, Frieda, recalls explaining to the surgeon that her mother's strong religious faith coupled with her views about brain injury meant that 'this isn't a complicated or fearful situation. You must let her die if that's a better outcome for her.' In another family a mother tried to intervene when she learned that doctors were planning to perform a decompressive craniectomy on her son. She refused permission – saying 'Let him die peacefully'. However, this mother was over-ruled by the consultant who reportedly explained the legal situation (correctly): 'because he's an adult we don't *need* your permission' (F7).

Mechanical ventilation and/or tracheostomy

Families usually reported that their relative was intubated and placed on ventilation in the immediate aftermath of the emergency. A 'window of opportunity' to refuse such interventions on behalf of someone who might prefer not to be treated can involve subsequent withdrawal of mechanical ventilation (extubation) and refusal of a tracheostomy operation (Chotirmall *et al.* 2010). This option was offered to two families, but both patients continued to breathe on their own.

For most families, however, the option of turning off the ventilator was never discussed and nor was the decision to wean the patient off the ventilator and put in a tracheostomy. Some might have refused had they known; others felt they had no choice but to consent –

although neither their refusal nor their consent would have been legally binding. Shula (F12) reluctantly agreed to a tracheostomy for her husband (despite knowing his clearly stated prior views which she felt strongly suggested that he would not have wanted one). She consented in order to ensure his comfort and to allow a full assessment to be carried out on his ability to breathe. Similarly, a member of another family felt there was no choice but to go along with the tracheostomy: ‘She needed ... either to die or to be made more comfortable, and since no one was going to let her die, she had to be made more comfortable’ (F11).

Only one family volunteered that they had been made aware of the potential significance of the decision to perform a tracheostomy. Tania and Ian (F4) had accepted that LSTs would be withdrawn from their son, and were willing to go along with this – but encountered an unexpected reversal when they returned to the hospital the following morning and met with a different consultant, one with a more ‘optimistic air’ who ‘didn’t mention anything about us saying goodbye to Charles. It was a completely different track. He started talking about fitting a tracheostomy. And we were absolutely staggered.’ Tania recalls the new doctor saying that there would be ‘no way back’ once a tracheostomy had been performed because ‘there’s no life support machine to turn off’. However, as a shocked and grieving mother, she could not understand the implications of this:

Tania: ... we came back the next day I suppose expecting to be asked about having the life machine turned off. But we weren’t. It was this other man wasn’t it, and he uhm he ...

Ian: ... gave us a bit of hope.

Tania: Yeah! And he just said, you know, ‘he’s young’, and he just had this feeling ... And you want everything to be okay. You want to believe the good things, and we didn’t want to lose Charles, we were in total shock, so we agreed to the decision to have the trachy fitted (T4).

A ‘window of opportunity’ for non-treatment with mechanical ventilation can also arise much later when the patient suffers respiratory infections. Imogen (F3) recounts how, having been away for a weekend, she returned to visit her PVS husband in the care home where he’d been resident for the last 18 months. However, she found he had been transferred to hospital and placed on a ventilator:

Imogen: And they said, ‘he can’t go back because he needs a special ventilator’. And I said, ‘why does he need a special ventilator?’ They said, ‘because his breathing isn’t good, he’s getting pneumonia’. And I was just thinking, ‘what does it matter!’ you know. But they insisted ... And eventually they sent him back with this huge machine and big thing on his face which he couldn’t breathe, he used to choke with it ... I just said, ‘what good is it? Why?’ you know, it’s just horrendous –

Inter: So they were saving his life.

Imogen: Yeah. And what for? ... and I said to one of the doctors, ‘what if I don’t want this anymore? What if we don’t want this, what do we do?’ And that’s when he said, ‘you’ll go to prison if you do that’ (F3).

Imogen subsequently found a different doctor, about two months later, who was willing to authorise non-treatment (of a different infection).

Resuscitation

Like anyone else, people with brain injuries can die from cardiac arrests – especially since attempts at resuscitation are often unsuccessful, and even if the heart is restarted people are likely to suffer (additional) brain injury from oxygen deprivation (Timmermans 1999). Some families had been asked if they would agree to having a 'do not attempt resuscitation' (DNAR) order placed on their relative's records. Some had resisted this, at least at first. Rhiannon, for example, explains: 'My reaction at that time was, "You're asking me to make these decisions – how do I make these decisions? I'm fighting for my little girl's life".' (F2). Distraught, she rang a brain injury charity for support. The advisor encouraged her to resist the doctor's suggestion on the grounds it was 'too early' to make this decision.

Eventually, however, all of these interviewees agreed to – or in some cases successfully instigated – a DNAR order. Several years after her initial horror at being asked this question, Rhiannon responded very differently to another doctor's question about resuscitation: 'I said: "No, I wouldn't want her resuscitated" ... She's had enough. She's had four years of this, you know' (F2). Daisy, who had initially also resisted DNAR on her brother's records, similarly came to accept it because: 'I suppose seeing his experience and seeing other people's experience [in the care home], I think life and death had different meanings for us then' (F10).

Antibiotics

Antibiotics can constitute LSTs in the face of possibly life-threatening infections – the single most common of which is pneumonia. One study of patients with severe traumatic brain injury found that 27% had pneumonia on transfer from the intensive care unit and a further 12% developed pneumonia during rehabilitation (Hansen *et al.* 2008). This means that the 'window of opportunity' for allowing death opens again and doctors might propose a non-treatment option. For example, Daisy recalls that when her brother developed pneumonia a few weeks after his accident, a doctor suggested that 'it might actually be better for him to be dead'. However, the entire family reacted with fury and resistance: 'No, he would absolutely want the antibiotics. We're going to *fight* as much as we can, do everything we can [to keep him alive]' (F10). Members of another family, by contrast, tried to oppose administration of antibiotics to their relative when she developed pneumonia a few weeks after her accident – but their attempts failed:

When she had the pneumonia she was clearly in *great* distress and should have been allowed to die. And instead they pumped her full of antibiotics ... She should not have been given those antibiotics. I know she may have survived and everything, but I spent so much time with her, I don't think she would have. She really was near death then (F11).

Some family members now talk of hoping for pneumonia – one, for example, spoke of 'longing' for her relative to develop pneumonia because 'it would be the kindest way for him to die'. However, even when families are offered, and accept, the option of no 'aggressive' treatment, pneumonia – 'the old man's friend' – may turn out not to offer the hoped-for release for many of these otherwise healthy individuals. Nor may it seem 'kind' at the time. Fiona's mother and sister were presented with the option of withholding antibiotics when she fell ill with a chest infection soon after her accident and they agreed to 'let fate take its course' (Ann, F1) because 'we felt she'd suffered enough' (Bea, F1). Fiona survived this first bout of

pneumonia without antibiotics and also without any evidence of good palliative care. Several years later, and despite believing that Fiona would rather not be alive, Bea found herself reversing the long-standing agreement *not* to treat Fiona's life-threatening illnesses, prompted to intervene by Fiona's apparent distress. Shula similarly ended up intervening to obtain antibiotics for her husband's pneumonia – in spite of her belief that he would rather be dead:

He had a lot of phlegm and was choking – and that's horrific, watching someone who's going through like that. And again you think, 'Can I really be that cruel?'. You can't. If you had a dog you'd give it a fucking pill (F12).

Artificial Nutrition and Hydration

All the families we interviewed report that, at the outset, their relative's swallow mechanism was severely impaired or entirely absent. All these patients were originally given nutrition and hydration via a nasal-gastric tube, and most now receive it by a gastric feeding tube inserted through the abdomen. According to our interviewees, clinicians rarely discussed the initial insertion of feeding tubes (of either kind) with the families except insofar as the latter was presented as more comfortable for the patient than is nasal-gastric feeding (and was sometimes actively pursued by families for that reason).

For many severely brain-injured patients, the only thing – other than 24-hour nursing care – that remains essential for long-term survival is artificial nutrition and hydration [ANH]. Clinicians have a legal duty to consider whether or not they can justify ongoing ANH (or any other treatment) as being in the patients' best interests. One alternative to waiting for the patient to die of pneumonia or other infections is to withdraw artificial nutrition and hydration – or not to replace a dislodged tube – in the knowledge that death from dehydration is the certain result. Under the law in England and Wales all decisions relating to the withdrawing or withholding of ANH in relation to an adult in a vegetative or minimally conscious state must be referred to the Court of Protection in compliance with Practice Directive 9E (British Medical Association 2012). Current case law suggests such applications are likely to be successful for only five of the fourteen patients in our sample – those with a diagnosis of PVS – and then only if this PVS diagnosis is independently confirmed by a medical professional acting for the Official Solicitor. However, once a PVS diagnosis is so confirmed 'the conclusion follows automatically that the patient's best interests dictate the termination of assisted feeding' (Mason and Laurie 2011: 510). The responsibility lies with hospital Trusts to take the lead in making application for termination of ANH where they consider the patient to have a likely PVS diagnosis. However, the small number of court applications since *Bland* demonstrate that this 'way out' for PVS patients is rarely pursued and our interviews suggest that clinicians and Trusts are not always taking responsibility for initiating discussions about this with families. For example, although the patients in Families 1 and 2 were both diagnosed as PVS (from anoxic brain injury) several years ago, family members did not appear to know who was in charge of medical treatment decisions, and both mothers believed (incorrectly) that the burden of responsibility for any end-of-life decisions lay with them. One commented: 'really, we're forcing them to stay alive ... they should be given the option ... of either being given something that will do something quickly, and I think that would be the better option, or the option of taking away their nutrition and their drink'. But she added: 'I'd feel like a monster suggesting that' (F2).

Although it seems that *some* interviewees might be receptive to ANH withdrawal as a way out for their relatives, other interviewees had been horrified when this option had been raised

by clinicians. Their horror was not because they did not want their relative to be allowed to die, but because 'starving and dehydrating' anyone to death was abhorrent to them. A father said: 'When they told me [about ANH withdrawal] I felt like screaming'; a mother commented 'I would rather do it [kill him] myself.' Some interviewees had thought about 'mercy killing'. One mother referred to a news story about a woman who killed her severely brain damaged son and received a life sentence for murder. She commented: 'everyone who's been in our situation can relate to that ... I wish I had her courage'.

Even where some family members accepted ANH withdrawal as the 'least worst' option ('barbaric – but then being kept living that way is barbaric') a family consensus could not always be reached. Interviewees also expressed fear of the court hearings ('I'd feel like I was on trial') and one interviewee had witnessed the stress placed upon another family going through legal proceedings to withdraw ANH: 'it just went on and on and on, and the situations they put him in, the process they put him through, it was just as if he wanted to get rid of her' (F2). The way the court proceedings played out, she said, led to the destruction of the whole family. It is clear then, that there are unique legal, clinical and emotional difficulties in withdrawing ANH from this patient group, even from those with an uncontested PVS diagnosis.

In sum, our analysis of these families' experiences has tracked a series of key decision points from the triggering event onwards. For most patients the potential 'window of opportunity' for death by having LSTs withheld or withdrawn has now almost closed. Interviewees who believe that their relative would have refused treatment in intensive care are often angry that their relatives' own wishes did not prevail. One reports: 'first they said it was too soon, now they say it is too late' and she says that her relative was treated 'like a lump of meat, that we'd somehow animate'. Others feel their relatives were 'experimented on' or used as 'guinea pigs' in an area where medicine offers few answers. Those who believe that their relative would have wanted to receive LSTs and be given a chance to recover now feel they have been betrayed: a son comments that his mother would have been 'horrified' by being kept alive in her vegetative (or minimally conscious) state: 'We were a candid family and talked about these things. Though when she talked about it she meant senility – this is much worse than she would have imagined' (F8). A wife recalls similar discussions with her husband and says 'He would never have wanted to live like this ... he would just hate it', adding 'it seems too cruel to subject a human being to that ... if it was an animal you would put them down' (F6). Families who fought to give their loved ones time (and resources) to enable them to emerge from a vegetative state have come to regret that the person now has some degree of consciousness. A sister says:

When he's asleep he looks peaceful. And as he wakes up he grimaces and roars and is so miserable – of course, because you're waking up into a nightmare. And it's always awful watching him wake up ... He is very aware of his situation, and his situation isn't one you'd want to be aware of (F10).

A daughter in another family simply states: 'I wish that mum was in a completely vegetative state and had no awareness at all really' (F14).

Families involved in delivering daily care often described now feeling abandoned and viewed as an awkward inconvenience by medical professionals. They also spoke of witnessing – even contributing to – the patients' distress, pain, and lack of dignity. A sister who fought for years to ensure good rehabilitation for her brother describes how after eventually obtaining the best possible care for him, the situation became more stark: 'The new care home was just exceptional ... So then it was, 'Okay, the place is pretty much perfect, [but] ...

He's still in hell.' (F10). The whole family then came to believe that 'Rather than working in his best interests we were working against them. We were helping the ongoing torture' (F10). A mother from another family concludes: 'The ones that don't survive are the lucky ones' and describes her daughter both as 'not living' and (although she has a PVS diagnosis) as 'suffering':

She's had a lung collapsed, she's had C Diff [clostridium difficile] five times ... She's had pneumonia. She had to have a defib [defibrillator] fitted. She had a NG [nasal gastric] tube pushed down her nose for five months which kept coming out. And that's traumatic in itself. Having that pushed down all the time you know ... Amy feels pain (F2).

This mother believes that even the things she does to care for her daughter can distress her, and she emphasises Amy's lack of choice:

And her hands are crippled, you've got to straighten them and that's painful for her – you know her limbs are stiff. That's painful for her but she can't tell me to get off. It's all those things that she hasn't got a choice. I can remember my Mum being ill and my Mum saying 'I don't want this any more, I don't want any more'. And *she* had that choice (F2).

Many interviewees report that their experiences have profoundly influenced their perspective on LSTs for themselves. Tania told us: 'I have said to Ian [husband], 'If anything happens to me, do *not* let them near me. Do *not* let them operate. Just let me go' (F4). Several interviewees had written Advance Decisions (ADs) to refuse treatment in the event of their lacking the legal capacity to do so contemporaneously in future. In every case their ADs emphasised their prompt rejection of LSTs rather than waiting to assess the possibility of acceptable recovery. Daisy explains that witnessing what her brother went through means that now: 'I don't want *anything* the minute that my brain is damaged in any way' (F10). Shula similarly would now rather die 'prematurely' than take the risk of suffering the same fate as her husband. She has written an uncompromising Advance Decision, and explains: 'I appreciate I may die before my time is due but I prefer that than run the risk of [what's happened to Ralph]' (F12).

Conclusion

The research reported here contributes to the medical sociology literature which explores the social construction of death and dying (Kaufman 2005, Kitzinger and Kitzinger, in press) and, more specifically, to the emerging body of clinical and bioethical literature addressing the 'window of opportunity' for allowing death (e.g. Crippen 2005, Cochrane 2009, Honeybul *et al.* 2011, Kon 2009, Wilkinson 2011). Bioethicists have extended the concept of the 'window of opportunity' (traditionally used within medicine to describe a correlation between prompt treatment and maximised recovery) to describe – and to critique – current medico-legal practice which results in unnecessary time pressure for allowing death by withdrawal of life-sustaining treatments. Previous work has been philosophical and theoretical (e.g. based on decision theory, Wilkinson 2011) rather than empirical. We have contributed empirical research which addresses some of the key issues that arise for families whose experience of a relative's severe brain injury is shaped within the medico-legal concept of the 'window of opportunity' for allowing death. The experiences of the families reported

here highlight tensions, contradictions and problems in current practice and pose important challenges for clinicians, law-makers and policy-makers.

From the bioethical perspective the key problem of the medico-legally constructed 'window of opportunity' for death is that the window is open early on at the point when the prognosis is most uncertain and closes later when there is physiological recovery (such that LSTs may no longer be required to sustain life) and more certain prediction of the likely extent of the person's impairment (Wilkinson 2009: 512). This means that there is a high human cost attached to prognostic uncertainty both in terms of keeping alive people who their families believe would rather have died, and conversely – since clinicians, unlike families, are often aware of the time pressures created by the 'window of opportunity' for death – letting die (while the 'window' is still open) some people who would have recovered to an acceptable quality of life (Cochrane 2009, Savulescu 1993).

There are many attempts to address the problem. Improved prognostic testing is widely recommended (Wilkinson 2009, Madder 2012) and in the field of brain injury this includes, for example, research into the use of electroencephalography and fMRI brain scanning. There is also ongoing research into how best to protect and to repair the human brain (e.g. hypothermia treatments, stem cell research) and how to provide rehabilitation and support to allow people, wherever possible, to find a life 'worth living' in circumstances they might previously have seen as intolerable. However, the problem of the closing 'window of opportunity' for death for those patients who (according to the families we have interviewed) would *still* wish to refuse life-sustaining treatment cannot be solved simply by better medicine and science or better rehabilitation and care.

Another suggestion is 'to defer decision-making until greater certainty could be achieved, and then resort to euthanasia if a poor outcome were predicted' (Wilkinson 2009: 512). The availability of active euthanasia would mean, as bioethicists (e.g. Savulescu 1994, Wilkinson 2011) have pointed out, that the concept of a 'window of opportunity' would become irrelevant, and those who have become aware of it (like those of our interviewees who told us about their ADs) need no longer feel time pressures to refuse LSTs before it becomes 'too late'. As Cochrane argues: 'if it were just as easy to "pull the plug" later, most patients would undoubtedly wait for more prognostic certainty' (Cochrane 2009: W5). Our data certainly suggest the need for serious discussion about the extent to which clinicians should be able to actively aid dying rather than simply withhold or withdraw treatments. From *Bland* onwards it has been stressed by the courts that 'it is unlawful to kill a person by means of a positive action whatever may be one's intentions. It follows that termination of the life of an incapacitated patient can only be lawful if it is ... achieved by way of a failure to act' (Mason and Laurie 2011: s18.13). Public discourse about the ethics of physician-assisted dying relates almost exclusively to people who have the legal capacity to request it and the 'dignity in dying' movements sometimes explicitly distance themselves from advocacy for the right to die of those without legal capacity (Richards 2012, Tucker 2012). However, since the law sometimes recognises that being kept alive is not in someone's best interests (Mason and Laurie 2011 s15.124) many of our interviewees find it hard to see why the only lawful way in which their relative's death can be accomplished is by treatment withdrawal, rather than allowing the same end to be achieved more quickly (e.g. through a lethal injection). While the BMA (2007: 18-19) maintains a strict differentiation between actions which foreseeably lead to the patient's death, on the one hand, and those intended to end the patient's life on the other, some countries, such as France, have already reviewed palliative care in brain injury cases to require the active use of terminal sedation and/or analgesia to eliminate any suffering

possibly caused by treatment withdrawal (Baumann *et al.* 2011). As Farsides and Dunlop (2001: 1483) say:

Although the moral, social and political reasons for wanting to maintain a prohibition on ending someone's life are powerful, it is important to acknowledge that these deny individuals the right to make the full range of choices that logically follow from a decision that life is not worth living.

We end by suggesting an additional six practical steps which, within the constraints imposed by the current medico-legal context of the 'window of opportunity' for death, might nevertheless have helped the families involved in our research.

First, better decision-making processes in compliance with the Mental Capacity Act 2005 could have helped the four families in our sample who were clear early on that their relative would not have wanted to be kept alive. Clinicians in England and Wales already have the legal right (and duty) to withhold or withdraw all 'futile' and 'burdensome' LSTs from brain injured patients except (following *Bland*) ANH. A properly conducted 'best interest' meeting might enable, for some patients, the early withholding or withdrawing of surgery, mechanical ventilation, and/or antibiotics, so allowing the possibility of death well before the 'window of opportunity' has closed. In three of these four cases it seems that the person's values and beliefs and the judgments they would have made (as reported by the family) were either not incorporated into the decision-making at all, or that they were given low priority.

Second, good quality diagnosis, care and information are fundamental to good quality decisions about whether and how to make use of any 'window of opportunity' for death. Some interviewees were concerned that their relative had not been given the opportunity for appropriate assessment and rehabilitation and some thought that the patient's apparent pain or distress was at least in part a consequence of not being cared for properly (e.g. inadequate pain relief, as reported by Daisy, F10): allowing death is not an acceptable 'solution' to the problem of poor quality care. Only when interviewees were confident that their relative was being treated with skilled attention, compassion and respect, and only when they felt well informed (or trusted that the decision-makers were well informed and well motivated), were they in a position to assess his/her state under optimal conditions and consider what the patient would have wanted (see Latchem and Kitzinger 2012).

Third, it seems from our data that at present PVS patients who miss the early window of opportunity for death are then sometimes left in limbo with continuing treatment provided by default, and without 'best interest' discussions, as required by the Mental Capacity Act 2005. Even those families who come to believe that the patient would now wish to refuse further treatment can find withdrawal a difficult issue to raise with consultants ('I'd feel like a monster'). Our findings suggest the importance of regular patient review, with the initiative for raising issues of treatment withdrawal coming from the clinicians. It might also help if ANH withdrawal (e.g. for PVS patients after one year) were adopted as a default position, rather than requiring a decision from the courts. Some bioethicists argue that once a PVS diagnosis is confirmed then (in the absence of any advance stated wishes to the contrary) withdrawal of ANH should become the default position with the burden of justification on those who would continue ANH (Constable 2012).

Fourth, since a court application proves yet another obstacle (and causes delay) for clinicians and families trying to act in the patient's best interests, the British Medical Association (BMA 2007: s 21.1) has already recommended that clinicians should be able to withdraw ANH from PVS patients – as they can for demented or terminally ill patients –

without recourse to the courts. Removing the obstacle of an application to the Court of Protection, or alternatively establishing a fast-track streamlined process for such cases, would help insofar as withdrawal of ANH could be assessed and decided upon by clinicians without delay at the point where there is agreement as to its appropriateness. It would also prevent families feeling intimidated by the court processes (an issue raised by two families in our research). Such changes in process might help decision-making in many cases. However, this would probably do nothing to counter some families' perception of ANH-withdrawal as a cruel (even 'barbaric') way to allow a person's life to end. Wherever consideration of ANH withdrawal is discussed there will need to be good information and support for families and indeed staff – as already recommended by the BMA (2006: 111).

Fifth, if decisions are made to withhold/withdraw any LSTs then patients should *always* be provided with good palliative care and not just left to 'die of neglect' – as seems to have been experienced by some of our families, who report seeing their relative simply put in a side room and abandoned to suffer pneumonia, free of 'aggressive treatment' but also without any apparent support to alleviate the patient's signs of distress (or that of the family). The failure to provide palliative care may not only cause unnecessary suffering for some patients, but can also mean that families are unwilling to cooperate with clinical teams in considering any subsequent 'window of opportunity' for the patient to die (as happened with F1).

Finally, if the people whose families we interviewed had made (valid and applicable) Advance Decisions [ADs] outlining their prior wishes – and if they had written that they would not want to be kept alive with severe brain injury (or in a vegetative or minimally conscious state) – then they might have been allowed to die. There has been no government-led promotion of ADs in the UK, there is little public awareness of their existence, and only around 3% of the population has one (*Compassion in Dying* website 2011). Increasing awareness of ADs as an option, and, crucially, providing support in drafting them *appropriately* so that they are likely to be relevant and applicable in the situations to which the person intends them to apply, would be one way forward. Despite ongoing debate about both the philosophical underpinning and the practical efficacy of Advance Decisions (e.g. Fagerline and Schneider 2004), their value has been confirmed in a recent Court of Protection case in which an AD was the basis on which a judge authorised the removal of a ventilator from a man with motor neurone disease, allowing him, as he had wished, 'to peacefully end his life' (*X Primary Care Trust v XB* (2012) EWHC 1390 (Fam), (2012) MHLO 54).

In conclusion, our analysis has explored the 'window of opportunity' through the lens of family experience. We show that some people believe that their relatives are being kept alive against their wishes, and this seems to be partly because the 'window of opportunity' for allowing death has closed and there seems to them to be no legal or humane way of releasing them. We urgently need to invest in ensuring the highest quality of care for these patients (and support for their families) and to consider all the options for an ethical response to their situation. Our research also suggests the need for reflection on the social and legal context in which society is dealing with such issues, and the need to take positive action to prevent people in future becoming trapped in this way, or, conversely, losing the opportunity for meaningful life because the risk of a 'fate worse than death' is too great. The situation at present is unsustainable and unethical.

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