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Judicial oversight of life-ending withdrawal of assisted nutrition and hydration in disorders of consciousness in the United Kingdom: A matter of life and death

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Abstract

Mr Justice Baker delivered the Oxford Shrieval Lecture 'A Matter of Life and Death' on 11 October 2016. The lecture created public controversies about who can authorise withdrawal of assisted nutrition and hydration (ANH) in disorders of consciousness (DOC). The law requires court permission in 'best interests' decisions before ANH withdrawal only in permanent vegetative state and minimally conscious state. Some clinicians favour abandoning the need for court approval on the basis that clinicians are already empowered to withdraw ANH in other common conditions of DOC (e.g. coma, neurological disorders, etc.) based on their best interests assessment without court oversight. We set out a rationale in support of court oversight of best interests decisions in ANH withdrawal intended to end life in any person with DOC (who will lack relevant decision-making capacity). This ensures the safety of the general public and the protection of vulnerable disabled persons in society.

Keywords

Decision-making, disorders of consciousness, end-of-life care, ethics, hydration, law, neuroscience, nutrition, treatment withdrawal

Background

Mr Justice Baker delivered the Oxford Shrieval Lecture entitled 'A Matter of Life and Death' at Oxford in the United Kingdom (UK) on 11 October 2016.[1]

He recommended continuation of court oversight in decisions related to the withdrawal of assisted nutrition and hydration (ANH) in a subset of disorders of consciousness (DOC): permanent vegetative state (VS) and minimally conscious state (MCS). This legal oversight is a procedural requirement under Court of Protection Practice Direction 9E:

> Cases involving any of the following decisions should be regarded as serious medical treatment for the purpose of the Rules and this practice direction, and should be brought to the court: (a) decisions about the proposed withholding or withdrawal of artificial nutrition and hydration from a person in a permanent vegetative state or a minimally conscious state . . .[2]

This lecture was a response to several UK commentators including Turner-Stokes and Kitzinger who argued for permanently abandoning the procedural requirement of court oversight in all VS/MCS cases because these proceedings unnecessarily delay ANH withdrawal and death.[3–7] In order to avoid such a potential delay due to drawn out court proceedings, Mr Justice Baker proposed the adoption of a pre-proceedings protocol 'which spelt out the obligations on the parties to ensure that all necessary steps were undertaken before the start of the case, including independent testing of the level of consciousness'.[1] Mr Justice Baker did not suggest a permanent or indefinite court involvement. Strikingly, his call for conditional involvement was based on the same line of reasoning that prompted him to advocate continued

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independent judicial oversight of requests for withdrawal of ANH:

> I certainly would not wish to retain the obligation to apply to court indefinitely. The time may come when applications to the court are unnecessary save where there is a dispute. But for my part, I do not believe that we have yet got to that point. When the House of Lords in *Bland* [*Airedale NHS Trust v* Bland (1993)] predicted that the time would come when applications would no longer be required as a matter of routine, their Lordships anticipated that a body of experience and practice would be built up. But as I have, I hope, demonstrated above, *both medical science and the law are still evolving. Until such time as we have greater clarity and understanding about the disorders of consciousness, and about the legal and ethical principles to be applied, there remains a need for independent oversight . . . In my opinion, however, applications to the court should continue to be obligatory in all cases where the withdrawal of ANH is proposed, at least for the time being* [emphasis added].[1]

In *Airedale NHS Trust v Bland*, the House of Lords (legislative chamber of the UK Parliament) authorised – with family consent – ANH withdrawal in Anthony Bland who was in a permanent VS three years after a traumatic asphyxial brain injury:

> *Anthony Bland cannot see, hear or feel anything. He cannot communicate in any way. The consciousness which is the essential feature of individual personality has departed for ever . . .* [i]n order to maintain Anthony Bland in his present condition, feeding and hydration are achieved artificially by means of a nasogastric tube . . . The *undisputed consensus of eminent medical opinion* is that there is no prospect whatever that Anthony Bland will ever make any recovery from his present condition, but that there is every likelihood that he will maintain his present state of existence for many years to come, provided that the medical care which he is now receiving is continued . . . [i]n that state of affairs the medical men in charge of Anthony Bland's case formed the view, which was supported by his parents, that no useful purpose was to be served by continuing that medical care and that *it was appropriate to stop the artificial feeding and other measures aimed at prolonging his existence* [emphasis added].[8]

The prevailing medical opinion then was that Anthony Bland had no consciousness and was unlikely to recover. The ruling in *Bland* also considered ANH to be medical treatment that can be legally withdrawn.

The public media and press's reporting on the Oxford Shrieval lecture caused medical and legal controversies in the UK because it drew attention to how clinicians may make life and death decisions about withdrawing ANH in incapacitated/disabled persons.[7] Turner-Stokes expressed dissent to Mr Justice Baker. She published a case series of VS/MCS patients who died under her care to demonstrate that 'clinicians regularly undertake best interests decision-making in conjunction with families that may include life and death decisions (sometimes even the *withdrawal or withholding of clinically assisted nutrition and hydration*); and these decisions can be made within the current legal framework *without necessarily involving the court in all cases*' (emphasis added).[7] Turner-Stokes argued that Mr Justice Baker's lecture had polarised and confused the public debate about ANH withdrawal in neurologically disabled patients who lack decision-making capacity and that: '[u]nfortunately, a moment of uncharacteristically imprecise language in Mr Justice Baker's lecture led to further confusion.' The imprecise language was related to Mr Justice Baker requiring court oversight in *all cases* of DOC. Currently, court oversight is only required in a subset of patients with DOC: those in permanent VS or MCS. There is no legal requirement in the UK for court oversight in uncontested cases of ANH withdrawal from patients in coma and DOC secondary to chronic degenerative conditions (e.g. dementia, Parkinson's disease, multiple strokes, etc.) or from patients in a VS that is not diagnosed as permanent VS.[7] Turner-Stokes later explained that Mr Justice Baker, in a personal conversation, had conceded that court oversight of ANH withdrawal was required in only a subset of DOC, i.e. a permanent VS or MCS as defined by the clinical guidelines of the Royal College of Physicians of London and required under Court of Protection Practice Direction 9E.[2,7] For further disclosure purposes, Turner-Stokes and Kitzinger co-chaired the working group of the Royal College of Physicians of London at the time that the clinical guidelines were developed for ANH withdrawal in prolonged DOC (VS/MCS).[9] The clinical guidelines have outlined the medical, ethical, and legal aspects of the life-ending ANH withdrawal procedure in patients who were unlikely to die rapidly after a 'ceiling of care' had been set, i.e. withholding additional treatment such as cardiopulmonary resuscitation, antibiotics, blood transfusion, and surgical and medical interventions for acute life-threatening emergencies (Royal College of Physicians of London,[9] p.70).

We focus our critique on ANH withdrawal rather the withholding of additional medical care (including ANH) since both Mr Justice Baker's lecture and the clinical guidelines primarily focused on the withdrawal

of ANH. Scientific, ethical, and legal problems with the above-mentioned clinical guidelines have been outlined elsewhere.[10] Here, we posit that ANH should not be withdrawn without court oversight in any person with DOC who has no relevant decision-making capacity and no advance directives because: (1) starvation and dehydration is certain to cause death without the presence of concurrent life-limiting disease or life-threatening illness and (2) the dying process by starvation and dehydration can last two to three weeks and can be distressful to both patients and their families.[11–13] We disagree with the legal and clinical stipulation (post-*Bland*) that ANH is medical treatment. Instead, as adopted in many other jurisdictions, we hold that ANH constitutes 'a basic compassionate care service rendered to disabled persons'.[10] We outline our rationale for advocating that court oversight should not be limited to VS/MCS but should include any person: (a) who lacks relevant decision-making capacity, (b) has no advance directives (through Advance Decision to Refuse Treatment or authorised by a Lasting Power of Attorney for Health and Welfare) regarding preferences in ANH, and (c) for whom ANH withdrawal is considered to end his (her) life or hasten death. Court oversight can ensure that the decision-making about ANH continuation or withdrawal is well-informed through: (1) consultation with independent neuroscientists for confirmation of diagnosis and prognosis of DOC and (2) weighing the relevant medical and non-medical components of best interests in the decision-making process. We think that court oversight is of practical importance for the safety of the general public and the protection of vulnerable disabled persons in society.

Contemporary neuroscience of consciousness

Recent advances in neuroscience research have influenced the legal proceedings and ethical questions regarding ANH withdrawal in persons with DOC since *Bland* in 1993.[8,14] DOC can develop from different causes. DOC can result from traumatic brain injury, acute asphyxia, post-resuscitation of cardiac arrest, or primary neurological conditions, e.g. stroke, dementia, multiple sclerosis, etc. Neuroscience research has discovered covert awareness in a wide spectrum of DOC or phenotypes.[15] Detection of covert awareness in DOC requires advanced neuroimaging technology with command-following or naturalistic paradigms.[16] A multimodal approach of functional neuroimaging and neuro-electrophysiological studies has improved the accuracy of the diagnosis of DOC and also offered therapy options in severely brain-injured patients.[17,18] The definition, characterisation, diagnosis and prognosis of the different phenotypes of DOC continue to evolve and have a significant influence on clinical practice.[18,19] The clinical guidelines have distinguished only three levels of DOC (coma, VS, and MCS) based on clinical assessment for the presence or absence of awareness and wakefulness.[7,9] However, the diagnostic accuracy of the guidelines' criteria and definitions of the three levels of DOC has not been validated scientifically. Cohort studies suggest that the rate of clinical misdiagnosis in VS is at least 41% and this error rate has not declined over the past 15 years.[20] Incorrect diagnosis can result in a fatal outcome because of premature withdrawal of medical care and ANH.[21] The clinical guidelines have not yet acknowledged the relevance of contemporary neuroscience advances to increase the diagnostic accuracy and expand on the available therapeutic options in DOC. Incorrect diagnosis and/or withholding of therapy in DOC violates the trust of families in the transparency and truthfulness of clinicians who are making life and death decisions on behalf of their loved ones.[14,22,23] The clinical guidelines have recommended that a neurological diagnosis and prognosis should be made at least within four weeks after the onset of prolonged DOC to determine futility of continued medical care and ANH (Royal College of Physicians of London,[9] p.58). Under these circumstances, we propose that court oversight can provide an additional safeguard by including independent neuroscience experts to confirm the clinical diagnosis and prognosis of DOC and to ensure that the decision-making processes are well-informed and as rigorous as possible. Life and death decisions in DOC should be supported by contemporary neuroscience, among other considerations, and not be based on outdated clinical guidelines.

Decision-making and best interests

The Mental Capacity Act 2005 (MCA) section 4(6) defines best interests decision-making (in the event of lack of capacity) as that which respects personal values, wishes, feelings and beliefs:

> [Best interests decision-making] . . . must consider, so far as is reasonably ascertainable – (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity), (b) the beliefs and values that would be likely to influence his decision if he had capacity, and (c) the other factors that he would be likely to consider if he were able to do so.[24]

However, values and beliefs about living with severe neurological disabilities can vary among patients and

families in a multicultural society such as the UK. In many instances, patients' values, beliefs and wishes about providing nutrition and hydration in the event of absent decision-making capacity are unknown. The values and beliefs of patients and families can differ from those that are held by clinicians who are charged with determination of best interests on behalf of their loved ones. Nevertheless, the UK clinical guidelines have empowered clinicians to be the final decision-makers of patients' best interests:

> [T]he responsible senior clinician has ultimate responsibility for healthcare decision-making based on judgement of what is in the patient's best interests, taking into account what the patient would want if they could express a view. (Royal College of Physicians of London,[9] p.56)

The clinical guidelines have excluded clinicians who object to ANH withdrawal based on *their* assessment of patients' best interests from decision-making.[9,10] Such objection is considered a 'conscientious objection' that 'may not, of course, be well informed' (Royal College of Physicians of London,[9] p.65) and 'if the individual clinician could not sanction best interests decision in one direction, they should hand over the care of the patient to a clinician who can' (Royal College of Physicians of London,[9] p.66). ANH withdrawal is the default direction in the clinical guidelines.[9,10]

Neuroscience studies have detected awareness and capacity for communication after 12 years in VS.[19] Notwithstanding the clinical guidelines appear intolerant of dissenting opinions seeking ANH continuation and providing more time (beyond 6 months post-non-traumatic brain injury, or 12 months post-traumatic brain injury) for potential neurological improvement:

> 'A formal best interests decision meeting should normally be held at least *within 4 weeks after the onset of PDOC* [prolonged disorder of consciousness]' (Royal College of Physicians of London,[9] p.58).
> '*Once it is known that a patient is in permanent VS, further treatment is considered futile. Processes to consider withdrawal of life-sustaining treatments, including CANH* [clinically assisted nutrition and hydration], *should begin on the basis of their best interests* [emphasis added]'. (Royal College of Physicians of London,[9] p.76)

The clinical guidelines allow overruling the objections from family members to ANH withdrawal:

> It should be made clear that a decision made in a person's '*best interests*' is not *necessarily the same as the whole family being happy* about a particular decision (for example, a family cannot easily be expected to say that they 'want' or 'are happy' to allow death) [emphasis added]. (Royal College of Physicians of London,[9] p.57)

This contradicts the stipulation of the MCA, section 4(5) on how best interests should be determined:

> Where the *determination relates to life-sustaining treatment he must not*, in considering whether the treatment is in the best interests of the person concerned, *be motivated by a desire to bring about his death*. The *values of patients and families may not be congruent with values of clinicians who are caring for them* [emphasis added].[24]

Therefore, clinicians' perspective of best interests may not be aligned with medical, ethical or legal systems. Determining best interests entails upholding certain fundamental human rights, such as the right to life, autonomy, dignity, and privacy.[1] Upholding these rights can in some cases lead to a decision of continuing instead of withdrawing ANH. Therefore, each DOC case is unique and life-ending interventions should not be considered without allowing due process with court oversight before actual ANH withdrawal:

> [T]he purpose of the best interests test is to consider matters from the patient's point of view, it seems likely that *the courts will now focus much more intensely on identifying the patient's wishes, feelings, values and beliefs* looking carefully at all statements, formal and informal, made by the patient at an earlier stage to a greater extent than hitherto. *As a result, although there will undoubtedly continue to be a strong presumption that it is in a person's interests to stay alive . . . There are also potential indignities in the withdrawal of ANH... It might be thought that taking human dignity into account when making these decisions will always lead to ANH being withdrawn. But it does not follow that a patient in a disorder of consciousness has no intrinsic worth. For family, friends and carers, and, I would suggest, society as a whole, such a patient may retain their essential human qualities* [emphasis added].[1]

The court is in a better position than clinicians to take into account and weigh all the components relevant in best interests decision-making. The court may disagree with the clinicians' assessment of best interests with regard to withdrawal or continuation of ANH. This was the case in Paul Briggs who was in MCS and on ANH in *Briggs v The Walton Centre NHS Trust*.[25] Mr Justice Charles emphasised the imperative role of the court system in guidance of clinicians in the 'reasonably

ascertainable' determination of best interests in persons with DOC:

> *A court can if necessary make binding findings of fact and it carries out the weighing exercise required by the MCA* [Mental Capacity Act] with the benefit of hearing evidence that is tested and argument. As a consequence, *it is likely to be in a better position to determine the existence of, and the weight to be given to, the matters* set out in s.4(6) [section 4 (6)] *of the MCA that are based on the past when P had capacity than, for example, treating doctors are*. So, if P's family are asserting that they favour a different conclusion to that reached by the medical team, it is likely that in many cases to be reasonable if not inevitable for doctors to give great and probably determinative weight to medical and ethical issues in their exercise of the MCA best interests test pending the resolution of the existence of the matters in s. 4(6) and the weight to be given to them by a court [emphasis added]. (*Briggs v The Walton Centre NHS Trust & Another*,[25] para 48)

Withdrawal of ANH and end-of-life care

The dying process by starvation and dehydration can be protracted and distressful. Dehydration lowers the pain threshold and enhances pain-evoked activation of the human brain.[26] Pain and distress from ANH withdrawal may not be reliably assessed and treated by traditional bedside clinical or physical signs.[10,12] Assessment of pain and nociception in DOC is clinically challenging without utilising appropriate advanced neuromonitoring technology. The dying process can be as long as two to three weeks following ANH withdrawal. Unrecognised and untreated pain and nociception is distressful to dying patients. Additionally, dehydration can diminish the analgesic potency of opioids and potentiates the neurotoxic side-effects.[27] The efficacy of sedatives is also altered by dehydration and can paradoxically worsen delirium, restlessness and agitation. General anaesthesia may be a last resort to manage refractory symptoms after ANH withdrawal.[9] It is likely that persons with DOC who die after withdrawing ANH experience unrecognised distress.[10,11] Indeed, Turner-Stokes and Kitzinger have used this argument in favour of permitting active euthanasia by lethal injection to end the lives of patients in DOC rather than starving and dehydrating them to death.[3,28] Instead of concluding that withdrawal of ANH, even under the best available care interventions, causes pain, distress, and thus harm to the patient, and, therefore, should not be recommended as an appropriate end-of-life intervention, these commentators advocate for the permissibility of active euthanasia to minimise the risk of patient harm when ANH is withdrawn. With that, however, they are implicitly challenging the good moral standing of withdrawal of ANH that they intended to defend.[3,28]

Withdrawal of ANH and death

Clinical guidelines have recommended '[w]hen drawing up a death certificate after withdrawal of CANH, the original brain injury should be given as the primary cause of death' (Royal College of Physicians of London,[9] p. 84). The chain of causation of death after ANH withdrawal would be listed on the death certificate as 'the immediate cause of death being bronchopneumonia, and the underlying cause of death . . . severe brain injury and its subsequent complications'.[7] Although immediate cause of death may be bronchopneumonia, its onset is secondary to dehydration, kidney failure, and administrated drugs rather than brain injury. Dehydration following ANH withdrawal alters the pharmacokinetics and pharmacodynamics of continuous infusion of opioids and sedatives. Cumulative increase in plasma concentrations of morphine and active metabolites and potentially toxic plasma concentrations can be reached in the terminal phase of dying.[29] The consequences of toxic plasma concentrations can include depression of cardiovascular and respiratory functions, of airway reflexes, and pulmonary aspiration. Postmortem measurement of plasma concentrations of these drugs can verify the proximate causation of death. It is a legal requirement that the death certificate is issued with an accurate list of medical diagnoses that reflect in truthfulness the proximate cause of death.

Conclusions

Current UK law requires court oversight in ANH withdrawal only in a subset of DOC, i.e. permanent VS and MCS. Advances in neuroscience have discovered covert awareness in a spectrum of DOC phenotypes and offered the possibilities of therapeutic interventions. The clinical guidelines have not acknowledged contemporary neuroscience advances in DOC to improve the diagnostic accuracy when making best interests decisions on ANH withdrawal. We urge for continuation of court oversight in VS/MCS and expansion of this judicial oversight to include any person with DOC: (1) who lacks relevant decision-making capacity, (2) who has no advance directives and preferences regarding ANH and (3) for whom withdrawal of ANH is being considered with the intent to end life or to hasten death. We think that court oversight is of

practical importance for the safety of the general public and the protection of vulnerable disabled patients in society.

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