Should doctors be the arbiters in decisions to withdraw artificial nutrition and hydration from minimally conscious and vegetative patients?

My project focuses upon the decision to withdrawal artificial nutrition and hydration from patients in a vegetative or minimally conscious state. More specifically, I respond to the ruling in An NHS Trust v Y (2018) (hereafter, NHS v Y), by asking, should doctors be the ultimate arbiters of these decisions, according to the nature of the decision and the doctor's role?

The landmark case of Airedale NHS Trust v Bland (1993) (hereafter, Bland) ruled that indefinitely prolonging a life in a vegetative or minimally conscious state may not always be in the patient's best interests and hence that withdrawing ANH can be legal. The question of 'who decides' was granted legal clarity in NHS v Y, a Supreme Court ruling which confirmed that doctors can withdraw ANH from patients in permanent vegetative and minimally conscious states (PVS and MCS) without recourse to the courts, providing there is agreement between the doctor and the family that this is in the patient's best interests.

Making this decision in the clinical setting has clear practical and economic benefits. Halliday et al. (2015) states that NHS economists estimate the average court referral process costs around £122,000, and Holland et al. (2014) highlight the emotional distress that delays in withdrawal can cause families.

Beyond its practical implications, the ruling in NHS v Y prompts us to reflect on the critical question of whether doctors should be entrusted with decision-making power in these cases. Wicks (2019) claims this ruling threatens the patient's right to life by removing a neutral advocate in the court, and Foster (2018) argues the ruling could lead to paternalistic decision-making orientated around biomedical need rather than patient wishes. However, in order to make a more robust evaluation of this ruling we must take a broader view. As Lord Browne-Wilkinson states in Bland, 'behind the questions of law lie moral, ethical, medical and practical issues of fundamental importance to society' (p877). These issues need to be evaluated in order to test whether the ruling in NHS v Y reflects a fair balance of perspectives. My project uses a multidisciplinary approach by looking at the sociological background, legal context and professional implications of the ruling in NHS v Y to assess whether doctors are well-placed as arbiters of these decisions.
Firstly, I track the court’s deference to the medical profession, particularly following the shift towards greater respect for patient autonomy demonstrated in the Mental Capacity Act (2005). Looking forward to NHS v Y, I have identified the element of deference in the ruling’s assertion of doctors as arbiters of these decisions and its reliance upon professional regulation. However, I argue that this deference can be dissociated from traditional, paternalistic notions of the term, in light of how the profession and its guidance has evolved to become more patient-centred, as suggested by Devaney and Holm (2018).

I also investigate the nature of the decision doctors are being asked to make: firstly how the concept of best interests has evolved to become more holistic, and secondly whether withdrawal of ANH from PVS/MCS cases ought to be categorized as ‘special cases’. My project considers that viewing PVS/MCS patients as deserving of a higher safeguarding standard than other patients is unjustified, and that the technicalities of diagnosis should not overshadow consideration of the patient's wishes. NHS v Y has rightly aligned these decisions with other life and death best interest decisions, however the significance of ANH and its withdrawal for families should be taken into account by doctors and discussed with sensitivity.

I then focus on whether clinical decision-making in the present day lends itself to withdrawal decisions, including discussion of the broader role of ethical decisions in medicine. Contrary to the concern that this ruling will incite paternalistic decision-making, empowering doctors to be arbiters of these particular decisions allows timely withdrawal of ANH when it is agreed to no longer be in the patient's best interests. I argue, therefore, that this model may demonstrate greater respect for the patient's wishes.

Paternalistic or idiosyncratic decision-making is mitigated against by the rigour of the professional guidance. I have considered that the measures which have been put in place within the guidance have created sufficient safeguards for the patient's right to life: consultation with those concerned for the patient's welfare, the expert 'second opinion' and the option to consult the courts.

My project concludes that the ruling in NHS v Y represents a positive step forward, asserting the doctor as the arbiter of these withdrawal decisions and recognizing their ability to develop and exercise sound ethical decision-making, for the ultimate benefit of the profession and its patients.

Although this project has advocated doctors as the appropriate decision-maker in these
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Written by Phil Greenwood
Wednesday, 14 August 2019 12:44 - Last Updated Friday, 13 September 2019 13:43

Sensitive and important scenarios, this must correspond with standards in clinical training. I recommend that medical schools ensure that they facilitate the development of sound ethical reflection and knowledge of the law to equip future doctors to face such scenarios. Incorporating this into a broader study of medical humanities would give students an appreciation of the profession's historical and sociological context as well as the narratives brought forwards by patients. This would encourage future doctors to properly evaluate their assumptions alongside patients' personal, religious and cultural values.

With heaviness of heart I recognise that the voices of PVS and MCS patients cannot contribute to this debate. Unless we are able to establish communication with these patients, the decision-maker must rely on second-hand accounts of previously-expressed feelings and values. It has been deeply moving to consider the impact of the decision-making process on the family, many of whom see withdrawing ANH as an impossibly difficult decision, but at the present time, the only feasible option to allow their relatives to die. This project also illuminates the need to encourage patients to draft advance decisions to refuse treatment where appropriate, ensuring these are properly documented and respected by healthcare teams.

I am incredibly grateful for the opportunity to explore this topic and extend particular gratitude to the IME for their financial support.

References

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