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Reflective Student Summary: Ventilation and when to stop this life preserving measure

How are the UK and developing countries, such as Nepal different in their ethical approaches to decision making in this area?

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Abstract

Mechanical ventilation in the intensive care unit poses many difficult questions for health care professionals in the UK, particularly regarding futility, despite guidelines produced on the matter. However, in countries such as Nepal where there are no available guidelines, how do clinicians make these life or death decisions and what are the important factors when deciding to discontinue a patient's life support?

Here, I present an interesting case involving prolonged mechanical ventilation in a gentleman with Amyotrophic Lateral Sclerosis seen during my medical elective in Nepal. There are significant differences in attitude to end of life care in developing countries such as Nepal, compared to the UK. In the UK, we follow accepted guidelines and practices in order to make difficult decisions surrounding end of life care and withdrawal of treatment. Financial issues appear to be the greatest influence on decision making in Nepal. However, a lack of a legal protocol for end of life care that considers capacity, overall benefit to the patient and best interests is also lacking. The massive disparity in health beliefs of their population compared with our own also plays a notable role. By understanding what drives these decisions, especially with regard to peoples' health beliefs, we can change our own practice in order to benefit ethnic minorities in our own country and give them a better experience of healthcare.

Introduction

The average length of stay on an intensive care unit (ICU) in the USA is slightly over 3 days.[1] In the case of a 48-year-old gentleman with Amyotrophic Lateral Sclerosis (ALS) in a hospital in Nepal, mechanical ventilation on ICU had been continued for almost 700 days. He appeared to have no quality of life as he could no longer close his eyes, communicate in any way or move. This poses an obvious ethical dilemma, and an interesting question.

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1 Hunter A., Johnson L., Coustasse A. Reduction of Intensive Care Unit Length of Stay: The Case of Early Mobilization. *Health Care Manag (Frederick)* 2014; 33(2):128-35.

Would this be allowed to happen in the UK, and if not, why not? The provision and standard of healthcare is widely considered to be far better in the UK than in Nepal, but this does not give reasonable explanation for his protracted, probably futile stay on ICU. Factors contributing to this clinical decision may revolve around the attitudes and beliefs surrounding healthcare in Nepal, healthcare funding, and the potential for legal ramifications of decision making in Nepal to be less severe than in the UK.

I will examine the legal standings in both the UK and Nepal regarding cases such as this, and then reflect on this case in order to assess and learn about the different factors surrounding the ethics of decision making regarding assisted ventilation here in the UK and in Nepal, and indeed, how they differ.

Legal Standings in the UK and Nepal

Wherever the patient is being treated, the issue of ventilatory support is a contentious one, involving some extremely tough decisions for patients, healthcare professionals and family.[2] NICE Guidelines in the UK state that Non-Invasive Ventilation (NIV) should be offered to a patient with ALS (a degenerative neurological disorder of the elderly)[3] at an appropriate time in relation to their symptoms and should be stopped at the request of the patient or if it is in the patient's best interests.[4] Invasive ventilation is not mentioned in UK guidelines. Guidelines also recommend that a multidisciplinary team (MDT) approach is essential in making these decisions.[5] In broader terms, the UK law states that "if there comes a point in a patient's care where a clinician comes to the reasonable conclusion that further continuation of an intrusive life support system is not in the best interests of the patient, they can no longer continue: by doing so would constitute the crime of battery".[6] However, in Nepal, no such guidelines or MDTs exist. Decisions on end of life care appear to be in the hands of the clinician in charge of a patient's care. The Nepal Medical Council outlines a 'code of ethics' for clinicians, but this document

2 Oliver D. Ventilation in Motor Neuron Disease: Difficult Decisions in Difficult Circumstances. *Amyotrophic Lateral Sclerosis Other Motor Neuron Disorders Journal* 2004; 5(1):6-8.

3 Young P.E., Kum Jew S., Buckland M.E., Pamphlett R., Suter C.M. Epigenetic Differences Between Monozygotic Twins Discordant for Amyotrophic Lateral Sclerosis (ALS) provide clues to disease pathogenesis. *PLoS One* 2017;12(8): e0182638.

4 National Institute of Health and Care Excellence. *Motor Neurone Disease: Assessment and Management (NG42)*. London: NICE; 2016.

5 Leicestershire and Rutland MND Supportive and Palliative Care Group 2014. *Pathway for preparing to withdraw non-invasive ventilation (NIV) in patients with MND*. Accessed via www.mndassociation.org/wp-content/uploads/2015/02/leicestershire-and-rutland-pathway-and-guidelines-for-withdrawing-niv.pdf.

6 Airedale NHS Trust v Bland [1993] 2 WLR 316.

doesn't mention any guidance on end of life care, medical futility, or best interests.[7] Nepalese law only goes as far as stating that it is 'the duty of a doctor to treat [a disabled] person on the priority basis and to commend and send him to the place where his treatment can be done'.[8] Nowhere in the code of ethics or in the "Health Legislations, Acts and Rules"[9] document, published by the Nepalese government, is there any elaboration of this. This begs the question: how do doctors know when to discontinue treatment, and in the absence of any guidelines, is the decision making process ethical?

Comparing and contrasting UK and Nepalese protocols will undoubtedly help to understand different cultures' attitudes to, not just life support, but a whole variety of health behaviours. It will also show the implications of making a poor decision. By reflecting on this, it will benefit my own decision making as a junior doctor and help me understand other cultures' health beliefs and why they carry out certain health seeking behaviours.

Reflection

Whilst on the ICU ward round at a hospital in Nepal during my medical elective, the medical team reviewed the patient described above. My first thought was that this man lacked capacity, had absolutely no quality of life, and no prospect of improvement. His state was comparable to that of a patient suffering from Locked-In Syndrome, in view of the fact this man had lost all voluntary motor function.[10] I thought of the guidance set out by the General Medical Council (GMC) regarding capacity: "make the care of the patient your first concern"; "respect their dignity"; "in the patient's best interests".[11] This man clearly lacked capacity, but it struck me that the treatment being given to him met none of the guidelines outlined above. And whilst being fully dependent on a ventilator and percutaneous endoscopic gastrostomy (PEG) feeding, and unable to communicate in any way, his mind was as it was 20 years ago. I imagined what sort of media storm a case like this would cause in the UK. Analogous perhaps to that of Charlie Gard, but doctors here seemed to think

7 Nepal Medical Council, *NMC – Code of Ethics*, accessed via www.nmc.org.np/information/nmc-code-of-ethics.html.

8 The Protection and Welfare of the Disabled Persons Act 2039 (1982) Date of Royal Seal and Publication 2039-8-6 (2 Nov. 1982) Act No. 13 of the Year 2039 (1982) (Nepalese Law).

9 Nepal's Quest for Health*; Health Legislations, Acts and Rules*.

10 McNair K., Lutjen M., Langhamer K., Nieves J., Hreha K. Comprehensive, Technology-Based, Team Approach for a Patient With Locked-In Syndrome: A Case Report of Improved Function & Quality of Life. *Assist Technol* 2017; 27:1-6.

11 General Medical Council 2008. Consent patients and doctors making decisions together. Accessed via www.gmc-uk.org/static/documents/content/Consent_-_English_0617.pdf.

it the norm. Having ruminated on the case for several days, and seeing the patient daily on the ward round, I returned to have an in depth look at the 700+ days of notes. I wondered what could have possibly motivated the medical team to continue treatment in this gentleman.

Amongst all the daily blood results and notes from the consultant, there were paragraphs of notes quoting family members of the patient and their wishes. I asked one of the junior doctors about this and he explained to me that the patient was an extremely wealthy businessman and his wife had sold their 15 houses and spent most of their life savings on her husband's treatment. When I questioned the logic in this, the junior further explained that she had refused to stop treatment as she believed that God would intervene, and by divine power, would reach down and save her husband. Despite an explanation from doctors that her husband would never improve, she refused to believe this, so doctors were obliged to continue life-sustaining treatment.

This case raises so many ethical and moral questions it is almost impossible to address them all fully. They primarily concern the cost of healthcare in poor countries, advanced care planning and power of attorney in patients who lack capacity, battery, and the continued treatment of a patient when no improvement is suspected. It also raises different cultures' views and perspectives of health and treatments and how medical professionals should deal with these.

The first question raised is that of money. In the UK, good healthcare "is based on clinical need, not an individual's ability to pay".[12] This is one of the key principles on which the National Health Service is based. As a result, there is no discrimination on the basis of how much money people have. However, in Nepal and many other countries, free healthcare to all is nothing more than utopian. This patient has been allowed treatment due to his wealth, regardless of whether the treatment given to him is ethically right or wrong. It must be considered whether there is a financial motive from the doctors at the privately run hospital. There may be an element of greed upon which doctors have made the decision to carry on treatment. Despite knowing, based on clinical experience, that this man will not recover, they continue treatment because his wealthy wife can pay for it. This raises the question of what happens to the patient's wife when she runs out of money. She will become homeless and financially unstable. The issue of money is one that would be solved by having a healthcare system like ours in the UK. Obviously though, these countries cannot develop or sustain that, so perhaps more help is needed from developed countries to

[12] Department of Health 2015. The NHS Constitution for England. Accessed via www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england.

aid places such as Nepal in developing a more organised, structured healthcare system. Perhaps one day with the correct help and guidance, they too can offer healthcare that does not discriminate against the less well off in society.

Another important aspect of this case – and probably the most important – is that of battery, and the doctors not acting in the patient's best interests. Battery is defined as "when a person intentionally and recklessly applies unlawful force to another".[13, 14] In medicine, this relates to gaining consent prior to any examination or intervention. Furthermore, one of the key principles of medical ethics is that of beneficence; that is, any healthcare professional should always act in the best interests of a patient.[15] This gentleman has not, to my knowledge, consented to prolonged, invasive ventilation in order to prolong life. Therefore, were the doctors right to continue an intervention which had not been consented for and was clearly not in his best interests? The term "futile" is a common word used in medical environments, but there is little research or consensus on an exact definition of the word.[16] It is broadly considered as any treatment which will not benefit the patient.[17] This can lead to ambiguity and difficult decisions for healthcare professionals. However, in this case, it seems clear to me that to continue life-sustaining treatment would indeed be futile and would not be in the best interests of the patient. Like in all cases though, there will have been a point in this man's illness where doctors may have thought his quality of life and prognosis was good enough to continue treatment. However, it is clear this point will have passed long ago in this patient's case. When assessing whether continuing treatment is beneficial for a patient, clinicians must consider if their patient is of moral concern. There are six criteria for moral concern[(13)]: this patient clearly is sentient; has the ability to feel pain, whether this be physical or emotional. Obviously, he is a human – his life is sacred (this may be a massive contributor in his wife's decision to keep treating him and may reflect the wider beliefs of the people of Nepal, including the doctors treating him). Autonomy is important – as he is lacking capacity, his wife seems to make decisions for him. She has the duty to make decisions in his best interests, as are the doctors, who in the UK would intervene if she was not fulfilling this duty. Regarding personhood, this man was mentally well prior to intubation,

13 Collins v Wilcock [1984] 1 WLR 1172.

14 Offences against the Person, Incorporating the Charging Standard, Crime Prosecution Service, accessed via www.cps.gov.uk/legal/l_to_o/offences_against_the_person/.

15 Coonan E. Perspective: Medical Futility: A Contemporary Review. *J Clin Ethics* 2016; 27(4):359-362.

16 Simon J.R., Kraus C., Rosenberg M., Wang D.H., Clayborne E.P., Derse A.R. "Futile Care" – An Emergency Medicine Approach: Ethical and Legal Considerations. *Ann Emerg Med* 2017 [Epub ahead of print].

17 Willmott L., White B., Gallois C., Parker M., Graves N., Winch S. et al. Reasons Doctors Provide Futile Treatment at the End of Life: A Qualitative Study. *J Med Ethics* 2016; 42(8):496-503.

and therefore, in theory, would retain the ability for rational thought. Patient is the fifth criteria for moral concern, which he certainly fits with. This says that doctors have a duty to all their patients and perhaps gives justification for continuing care when all seems hopeless. However, law puts a limit on this; in the UK, it is a battery to treat someone when there is no potential benefit,[18] but in Nepal this does not seem to be the case. Clearly, there are gaps in guidelines and protocols for clinicians in Nepal regarding end of life care and that lead them to make incorrect decisions. Finally, potentiality – this describes a justification for continuing treatment until futility is reached[19] – the question is whether futility has been reached in this case. From my limited experience and what I have seen and read, futility would seem to have been reached in this man, as he has no quality of life left.

Cases such as this must be addressed on case-by-case basis. There are no guidelines for these decisions to be based upon in Nepal. It must be extremely hard for a local clinician to switch off life support when in your view futility has been reached but the patient's family insists on continuing. Perhaps what's expected of clinicians in Nepal is different to the UK; the sanctity of human life is regarded as higher than anything else, and clinicians are expected to respect this. In the UK, clinicians have a duty to put their own views aside and act in the best interests of the patient but it seems that in Nepal, this isn't the case.

A third question raised in this case regards the lack of provision of Advanced Directives, Power of Attorney and DNACPR. No one caring for this patient knows what his wishes are regarding end of life care or for when he lacked capacity. This I find somewhat odd, as he had been treated in the neurology outpatient department of the same hospital in the early stages of his ALS. Had this scenario occurred in the UK, a plan would have been outlined early on, to decide the type of care as his disease progressed. Questions regarding end of life are undoubtedly difficult to ask and indeed answer, but in the UK, they should be routinely asked to older patients and reviewed regularly if already in place.[20] This, even in the UK, can be difficult to implement,[21] so in a country where there are different attitudes to human life and different health beliefs, this may prove even more difficult to put into practice. Even if his wishes were to be kept alive for as long as he has been, this is surely not in his best interests as he has

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18 Offence Against the Person Act 1861, Legislation.gov.uk, accessed from www.legislation.gov.uk/ukpga/Vict/24-25/100/section/42.

19 Jones J., Hale C. "Who is Worthy of Moral Concern" University of Birmingham Lecture 2013.

20 Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine, British Geriatrics Society, Alzheimer's Society, Royal College of Nursing et al. *Advance care planning*. Concise Guidance to Good Practice series, No 12. London: RCP, 2009.

21 Micallef S., Skkrifvars M.B., Parr M.J. Level of Agreement on Resuscitation Decisions among Hospital Specialists and Barriers to Documenting do not Attempt Resuscitation (DNAR) Orders in Ward Patients. *Resuscitation* 2011; 82(7):815-8.

no quality of life whatsoever. Clearly Nepal would greatly benefit in implementing more advanced directives, DNACPR orders and so forth, in order to prevent cases like this from happening again. However, a lack of education, an inadequate legal framework and lack of infrastructure constitute big barriers to this.

Whilst this case has posed many questions around the ethics of ventilation and removing of life-sustaining treatment, it has also revealed to me the cultural differences in the attitudes to healthcare. Whilst in Nepal I observed an entirely new culture, one that was completely alien to me. I observed that this culture extends to how people view health, what their definition of health is, and what their health beliefs are. Clearly the health beliefs of this patient's wife have influenced the decision-making process for his treatment. Whilst the doctors in charge of his case may have similar health beliefs to us in the UK – all doctors I spoke to has been trained in the USA – they can do little to change the outcome due to the wider health beliefs of the people of Nepal. Nepalese health seeking behaviours and perceptions of what influences health will be very different to our own, due to their cultural background and also possibly to their lack of social development and education.[22] When I work in places like Birmingham, where many cultures and ethnicities exist,[23] understanding peoples' health beliefs will be of great benefit to me in my future work as a clinician, not just in end of life care decisions, but regarding health behaviours. These different beliefs need to be addressed when considering guidelines in relation to particular patients, and when motivating patients to change health behaviours.[24]

22 Hassahya O.T., Berggren V., Sematimba D., Nabirye R.C., Kumakech E. Beliefs, Perceptions and Health-Seeking Behaviours in Relation to Cervical Cancer: A Qualitative Study among Women in Uganda Following Completion of an HPV Vaccination Campaign. *Glob Health Action* 2016; 9(1):29336.

23 Office for National Statistics 2012. 2011 Census: Key Statistics for Birmingham and its constituent areas KS201, QS201 & CT0010. Accessed via www.birmingham.gov.uk/downloads/file/4576/census_2011_ks201_ethnic_groupspdf.

24 Carr C.V. Minority Ethnic Groups with Type 2 Diabetes: The Importance of Effective Dietary Advice. *The Journal of Diabetes Nursing* 2012; 16(3).

Discussion

End of life decision-making process in Nepal is radically different from any developed country. Only around 3% of people choose to "limit or withdraw life-sustaining treatment" in central Asia, compared to 14% in Western Europe.[25] Various reasons explain this nearly 5-fold difference, including money, lack of education, different views of the sanctity of human life, lack of provision of advanced care planning, and very importantly, the different health beliefs and health seeking behaviours in Nepal. Understanding these health seeking behaviours and health beliefs have wider implications to us than just helping us to make end of life care decisions. It aids us in treating any health issue, from primary prevention to counselling and referring a patient to surgery. Health beliefs and wider cultural views in many developing countries are very different to our own, and if we are to improve medical practice for people of different cultures, we must gain insight into what drives their health decision-making.[26] Getting to grips with what influences end of life decisions in Nepal and other developing countries also can help us to reflect on our own decision making – whether we are being truly professional and not letting emotion or our own personal views influence us in our decisions. However, directly comparing Nepal's health system to our own is not practical, as whilst recommendations can be made to try and improve the state of health care there, these are extremely difficult to implement due to lack of funding, infrastructure and political stability. Unquestionably, basing all these views on one case is not reliable data. Potentially more research could be conducted to understand why clinicians take certain decisions regarding end of life care both here and in Nepal. This may help us to improve the decisions surrounding end of life care in countries such as Nepal in the future, and it will also benefit us in terms of aiding our own understanding of decision making in another culture, and how we can implement this when treating people of other cultures in our own practice.

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25 Lobo S.M., De Simoni F.H.B., Jakob S.M., Estella A., Vadi S., Bluethgen A. et al. Decision-Making on Withholding or Withdrawing Life Support in ICU: A Worldwide Perspective. *Chest* 2017; 152(2):321-329.

26 Allison J., Mulay S., Kidd M. Life in Unexpected Places: Employing Visual Thinking Strategies in Global Health Training. *Educ Health (Abingdon)* 2017; 30(1): 64-67.

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