Prolonging life for family: whose suffering is more important?

Advances in medical technology and organ support mean that withdrawal of life-support treatment(s) leads to an increasing number of deaths in intensive care units. Where a patient does not have capacity, withdrawing life-supporting treatment is a medical decision which must be made in the patient's best interests.

Intensive care patients with a poor prognosis are often actively managed with organ support to allow discussion with family members. This raises the question of whose suffering is more important: the patient's or the family's? Should the timeframe of withdrawal focus on minimizing the potential suffering of the patient or reducing the psychological impact of bereavement on the family?

Family-guided withdrawal

Bereavement is a natural process which should not be over-medicalised. Working in intensive care can normalise the emotional stress associated with acutely unwell patients, and it is easy to forget that the loss will have a lasting impact on family and friends. In a patient at high risk of dying on the intensive care unit, more than half of family members experience significant traumatic stress, with most having borderline symptoms of anxiety and depression (McAdam et al, 2010), let alone the emotional consequences of bereavement.

An acute admission to intensive care can rarely be predicted and the shock of unexpected death is a risk factor for increased psychological morbidity to family members (Lundin, 1984). When approaching palliation, the family's wellbeing must be considered. The opportunity to discuss any questions, come to terms with the prognosis and say goodbye to their loved one can provide emotional closure and promote the healthy cycle of grief.

Dr Silas Fuller, Junior Clinical Fellow in Critical Care, Department of Critical Care, St Thomas' Hospital, Guy's & St Thomas' NHS Foundation Trust, London SE1 7EH
(srsfuller@gmail.com)

Medically-guided withdrawal

It is very difficult to objectively measure pain or distress in a sedated patient. Heart and respiratory rate are often used as surrogate measures but are very non-specific. Dying intensive care patients can suffer beyond physical pain, primary symptoms being dyspnoea and oedema (Su et al, 2018) which could be refractory to treatment as a result of the underlying pathology. If the poor prognosis is certain, unnecessary extension of active treatment goes against the ethical principles of non-maleficence and beneficence. Continuing life-supporting treatment until there has been a family discussion is common, but at some point the priority must be the patient's comfort and withdrawal of active treatment remains a medical decision.

Unless there is a clear ceiling of treatment or advance directive, most patients in intensive care are managed on the basis of a best interests decision. The family are a key part of this discussion, along with the multidisciplinary team, when they are available to communicate a patient's previous wishes. In a Canadian study following withdrawal of treatment on intensive care, most family members (90.4%) preferred some form of shared decision making (Heyland et al, 2003). While they represent part of this best interests decision, family involvement in withdrawal of treatment decisions can cause them to feel responsible for the outcome. The family's role in medical decision making must also consider the context of cultural and religious differences and possible unrealistic expectations.

Low mood is common in critical care patients. A patient's requests for withdrawal of care or treatment are often taken in the context of his/her illness and met with psychological support and possible pharmacological intervention. It can be very distressing for staff members to continue medical care (particularly the nursing aspect) when patients are obviously suffering (Wiegand et al, 2019). Although this is always a decision based on the patient's own mental capacity, a request for withdrawal of care or treatment must communicate the patient's ongoing and apparently unbearable symptom burden.

The final, least savoury argument is about resource management. Prolonging a patient's life in the intensive care unit to allow further family discussions also prolongs the time during which another critically-ill patient may be denied potentially life-saving treatment(s).

Conclusions

Although there is an argument for both sides, either extreme (immediate withdrawal of treatment or prolonging a patient's life until all family concerns are addressed) is inappropriate. As with all dilemmas, the best time for withdrawal of life-supporting treatment depends on the details of each individual case. Symptom control can generally be achieved to keep patients comfortable enough to allow time for family to gather and for the critical care team to support them through the decision of end-of-life care and withdrawal of treatment. **BJHM**

Heyland DK, Rocker GM, O'Callaghan CJ, Dodek PM, Cook DJ. Dying in the ICU: perspectives of family members. Chest 2003 124(1):392–397. https://doi.org/10.1378/chest.124.1.392

Lundin T. Morbidity following sudden and unexpected bereavement. Br J Psychiatry. 1984 Jan;144(1):84–88. https://doi.org/10.1192/bjp.144.1.84

McAdam JL, Dracup KA, White DB, Fontaine DK, Puntillo KA. Symptom experiences of family members of intensive care unit patients at high risk for dying. Crit Care Med. 2010 Apr;38(4):1078–1085. https://doi.org/10.1097/CCM.0b013e3181cf6d94

Su A, Lief L, Berlin D et al. Beyond pain: nurses' assessment of patient suffering, dignity, and dying in the intensive care unit. J Pain Symptom Manage. 2018 Jun;55(6):1591–1598.e1. https://doi.org/10.1016/j.jpainsymman.2018.02.005

Wiegand DL, Cheon J, Netzer G. Seeing the patient and family through: nurses and physicians experiences with withdrawal of life-sustaining therapy in the ICU. Am J Hosp Palliat Care. 2019 Jan;36(1):13–23. https://doi.org/10.1177/1049909118801011

Anaesthetic and critical care dilemmas are coordinated by **Dr Yasser Mandour**, Anaesthetic Registrar (ST7), Royal Free London NHS Foundation Trust, London and **Dr Anna Petsas**, Specialist Registrar in Anaesthesia and Intensive Care, Guy's and St Thomas' Hospital, London