

## Occasional essay

# Futility, right to die, withdrawal of therapy and the ICU as a medical purgatory

I knew that it was going to be a long day. It was the morning round, the intensive care unit (ICU) was full, staff were racing around shouting orders at each other, telling me to cancel the cardiothoracic list 'because we had no beds' and the night resident began the hand over by stating that the first patient who had just been admitted, intubated, ventilated and paralysed, was an 81 year old man who had 'terminal' emphysema. He had had numerous hospital admissions for acute/chronic respiratory failure and had been oxygen dependent for the last 12 months. The last hospital admission was two and a half months ago, requiring a three-week period of mechanical ventilation and a prolonged convalescence in hospital. When he was finally discharged home he remained dyspnoeic and bed-bound. He had given strict instructions to his only daughter, with whom he lived, to ensure that the next time he was admitted he was not to be put on 'life support' again. What happened?

It seemed that the daughter found her father unconscious after returning home from a brief shopping trip. She called an ambulance and arrived with him at hospital to be asked by an accident and emergency (A & E) resident "do you want your father to be treated actively?" She had been his carer for the past 5 years, she was unmarried and her life revolved around him, he wasn't a burden to her, indeed she had enjoyed caring for him. To the question 'do you want your father to be treated actively?' her response could only be "of course I do. I want you to do everything possible". The ICU registrar was contacted and informed; "Remember Mr. X? Well he's back again and his relatives want every thing to be done". The dye was cast - thiopentone, suxamethonium, intubation, all in A & E, and pancuronium 12 mg i.v. 'to stabilise him for the trip around to ICU'.

The rest of the ICU ward round was a little simpler. The remaining four patients who had been admitted overnight had problems that resolved rapidly, and could be discharged to the care of their home team - the 'Cardiac's' could now be accommodated, and there was less shouting by the ICU staff. I asked the ICU registrar if she could organise the discharge of patients who were

admitted overnight so that I could "sit and have a chat to Mr X's daughter".

The daughter was rational and reasoned. She understood that her father's wishes had been contravened, yet when asked 'do you want your father to be treated actively?' she stated that she could not bring herself to make the decision to stop treatment.

I began by saying that her father was sedated and comfortable at the moment and that we were continuing to ensure that he remained so. However, there was no treatment available that would return him back to health. Her father knew this, and as his life was coming to a close it appeared that it was also becoming unbearable. If he required resuscitation, he had expressed a wish not be put on 'life support'. We did not have to make a decision; the decision had already been made by him. By withholding or withdrawing 'life support' we would simply be carrying out this wish. I stated that it was unfortunate that she had been confronted by a clumsy question of 'do you want your father to be treated actively?' because we treated everybody actively. We would provide all that was necessary to allow him a comfortable death. Currently, what we were doing was simply prolonging his death.

The daughter felt comfortable with the fact that her father would be taken from the respirator and provided with a peaceful end. She understood that we were adhering to his wishes and was relieved to find that she was not required to personally authorise his death.

Nobody seems to die any more; they have cardiac or respiratory arrests, and arrive in the ICU for further management. Perhaps it is because critical care medicine has promoted itself as a discipline that can reverse any illness? Perhaps futility can now only be defined by the intensivist? While the right to refuse treatment remains the patient's prerogative, who is going to be sued if the patient is brought into hospital, unconscious and against their wishes by their family?

Withdrawal or withholding treatment is an important part of the intensivist's practice and in some ICU's accounts for up to 90% of all deaths.<sup>1</sup> It is performed if the patient is brain dead, if the patient (or surrogate) refuses or withdraws consent for life support therapy, or medical treatment is deemed futile and simply prolongs suffering and an inevitable death.<sup>2-8</sup>

Brain death can be established relatively easily when standard criteria are met.<sup>9</sup> The relatives can be informed with absolute certainty that consciousness is lost forever.<sup>10</sup> However, the commonest reason for withdrawal or withholding therapy in the ICU is futility of treatment in the terminally ill patient,<sup>11</sup> although the reasons of futility and the patient's right to refuse treatment are often interwoven.

Concerning right to refuse life support therapy; by

the time the patient requires intensive care, unless a previous declaration has been made, they are usually incapable of making medical decisions, and the family is often asked to articulate the patients wishes, concerning the continuation of treatment.<sup>12</sup> In this regard, the relatives should not be asked whether *they* would want treatment continued or withheld for the patient, but in the knowledge of what is wrong, what the therapeutic options are and what the prognosis is, whether they believe that the patient would want 'life support' to be continued or withheld.<sup>12</sup>

Concerning futility, despite the numerous multi-variable intensive care scoring systems that have been proposed in an attempt to accurately determine the outcome of a critically ill patient, the predictive abilities of any of the currently used scoring systems are not accurate enough to make them prognostically useful, and all continue to show a failure rate of 15 - 20% in predicting outcome in individual patients.<sup>13</sup> For the moment, good clinical judgement guided by experience appears to be just as accurate.

Futility has both quantitative (i.e. likelihood of achieving a final outcome) and qualitative (i.e. likelihood that final outcome will be acceptable to the patient) aspects,<sup>14</sup> so one has to gauge the likelihood of survival as well as quality of survival when talking to the family. Yet, while futility should only be judged on likelihood of achieving a desired outcome, in practice other factors often influence the decision to withdraw therapy (e.g. clinicians tend to withdraw therapy if the organ failure has developed naturally rather than iatrogenically, if withdrawal results in an immediate death, or if withdrawal of therapy will result in a delayed death if the diagnosis is uncertain).<sup>15</sup>

Although it is inappropriate to offer futile treatment to the patient,<sup>16</sup> the process of withdrawal of therapy is a sensitive issue and usually only occurs when the family has come to terms with the prognosis. Although one response to dealing with a request for futile treatment (e.g. cardiopulmonary resuscitation) is to practice a 'slow code' (e.g. to go through the motions of performing cardiopulmonary resuscitation with the aim and hope that the patient will not survive), this 'sham' simply provides a prolonged and painful death in an attempt to satisfy distressed patients or relatives. It has no justification.<sup>17</sup> With honesty, goodwill and a close communication with all concerned, the decision to withdraw therapy will generally be reached with time.<sup>16</sup>

Once the decision has been reached, the relatives often ask 'how long will it take?', 'can I be with him/her when he/she dies?' and 'will there be any pain or distress?'

To determine 'how long will it take' requires experience, and it is best to give a tolerably wide range

(without losing the confidence of the family) on what is likely to happen. If the patient is mechanically ventilated with a high inspired oxygen and high catecholamine requirement, one may reasonably state that it should not take long (and when pressed perhaps 10 to 20 minutes), although I always state that the patient may die immediately or linger for hours, as we only ensure that they are comfortable and do not actively hasten death. Similarly, withdrawal of ventilation from a post cardiac arrest patient who after three days is still decerebrate or decorticate may result in a patient who is able to breathe quietly and comfortably for days before finally succumbing to hypoxia from sputum retention and bronchopneumonia.

'Can I be with him/her when he/she dies?' I find can only be answered with a 'sure', as any other response tends to be regarded suspiciously. I tend to follow it up with 'but you must realise that a dying patient can be a grim if not hideous sight'. I then outline some reflex changes that they may observe, so that they are fully aware of what to expect if these changes do occur (e.g. blue grey appearance, 'gurgling' breath sounds, eye opening and looking upwards, spinal reflexes of arm or leg movements, even opisthotonos).

Finally, withdrawal of life support (e.g. ventilation, dialysis, artificial feeding, life sustaining drugs) is not an abandonment of the patient, and to the question 'will there be any pain or distress?' the answer is that we will do all we can to relieve any suffering (e.g. opiates, sedation, etc.).<sup>18</sup>

Withdrawal of therapy is an important part of the intensivists activity yet it is rarely taught, often performed awkwardly or ignored with the ICU becoming a medical purgatory filled with patients who are 'treated to death'. Like all aspects of medical therapy, its management requires honesty, frankness, trust and a genuine concern for all who are involved. If it is regarded as a chore to simply 'tidy up' the ICU, lawyers will be called in.

## L. I. G. WORTHLEY

*Department of Critical Care Medicine, Flinders Medical Centre, Adelaide, SOUTH AUSTRALIA*

## REFERENCES

1. Karlawish JHT, Hall JB. Managing death and dying in the intensive care unit. *Am J Resp Crit Care Med* 1997;155:1-2.
2. Task Force on Ethics of the Society of Critical Care Medicine. Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill. *Crit Care Med* 1990;18:1435-1439.
3. Tomlinson T, Brody H. Ethics and communication in do-not-resuscitate orders. *N Engl J Med* 1988;318:43-46.

4. Ruark JE, Raffin TA, and the Stanford University Medical Center Committee on Ethics. Initiating and withdrawing life support. Principles and practice in adult medicine. *N Engl J Med* 1988;318:25-30.
5. Smedira NG, Evans BH, Grais LS, et al. Withholding and withdrawal of life support from the critically ill. *N Engl J Med* 1990;32:309-315.
6. Blackhall LJ. Must we always use CPR? *N Engl J Med* 1987;317:1281-1285.
7. Jennett B. Decisions to limit treatment. *Lancet* 1987;ii:787-788.
8. Luce JM. Conflicts over ethical principles in the intensive care unit. *Crit Care Med* 1992;20:313-315.
9. Conference of Medical Royal Colleges and their Faculties (UK). Diagnosis of brain death. *Br Med J* 1976;ii:1187-1188.
10. Pallis C. Reappraising death. *Br Med J* 1982;285:1409-1412.
11. Prendergast TJ, Luce JM. Increased incidence of withholding and withdrawal of life support from the critically ill. *Am J Resp Crit Care Med* 1997;155:15-20.
12. Luce JM, Fink C. Communicating with families about withholding and withdrawal of life support. *Chest* 1992;101:1185-1186.
13. Kirby RR, Civetta JM. Critical care. In: Brown DL, ed. Outcome in anesthesia. Philadelphia: JP Lippincott, 1988:184.
14. Jecker NS, Pearlman RA. Medical futility. Who decides? *Arch Intern Med* 1992;152:1140-1144.
15. Christakis NA, Asch DA. Biases in how physicians choose to withdraw life support. *Lancet* 1993;342:642-646.
16. Snider GL. Withholding and withdrawing life-sustaining therapy. All systems are not yet "go". *Am J Resp Crit Care Med* 1995;151:279-281.
17. Gazelle G. The slow code - should anyone rush to its defense? *N Engl J Med* 1998;338:467-469.
18. Brody H, Campbell ML, Faber-Langendoen K, Ogle KS. Withdrawing intensive life-sustaining treatment - recommendations for compassionate clinical management. *N Engl J Med* 1997;336:652-657.