

Commentary

ICU Cornerstone: A lecture that changed my practice

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Abstract

In 1982, the author attended a lecture by Professor Joseph Civetta dealing with the concept that, at times, the goal of care should be comfort rather than cure, and that inappropriate care prolonged dying and suffering. Efforts to improve end-of-life care subsequent to this had effects on care at a local level and at a state level. Intensive care providers should be leaders in the provision of appropriate and compassionate care at the end of life.

Keywords death, terminal care

It was in 1972 that I was first rostered to work in an intensive care unit. From the first day, I never wanted to work anywhere else. The list of changes and improvements is enormous, but one particular event and its consequence, more than any other, changed both my practice and my life. The event was a lecture by Professor Joe Civetta in 1982 in Sydney.

In 1980, I heard Joe speak in San Antonio about ways of using nurses' time better. I had just begun running a 'Continuing Education Meeting' in Sydney that was to focus on things I believed we had not thought about enough. I invited Joe to speak at this meeting in 1981, and he informed me that the date and work was that of his wife, Judy. She agreed to attend. Joe also wanted to come. I asked what he would like to talk about and he said he had a lecture on 'Stress, Death and Dying'. When I queried why anyone would want to listen to such a lecture, Joe responded by suggesting that if 1% of my patients developed renal failure and 10% died, then maybe I should know as much about dying as I knew about renal failure.

Joe's lecture in March 1982 totally changed my practice and that of many others who attended. The message was simple, and is, in a small way, discussed in one of Joe's papers [1]:

- Intensive care leads to situations where continuing treatment prolongs dying and suffering without producing survival.
- To determine when this point is reached involves consideration of objective data and emotive aspects such as patient wishes.

- The patient's wishes could sometimes be ascertained from speaking to the patient's family.
- There is a need to create an environment in which both health care providers and consumers could discuss the appropriateness of treatment and a peaceful death could occur when indicated.
- There comes a time when the goals of good medical care should be comfort rather than cure.

The concepts are not as dramatic now as they were then, because today there is a virtual industry surrounding the dying patient and the patient's family. But we were taken with Joe's concepts. Withdrawal of care was unusual in our unit at that time, and when it did occur it was often covert. Trying to improve the end-of-life care of our patients moved us rapidly to a situation where only 9% of our patients died when we were still trying to prevent dying with all our resources, and 12.2% became brain dead. In the remainder of the patients, treatment was withdrawn or withheld.

We began to talk to patients and families about appropriateness of treatment and about withdrawing and withholding treatment. After reading Majorie Sternberg's paper 'The responsible powerless' [2], we instituted regular meetings with the nursing staff at which the patients and the appropriateness of their care could be discussed in more depth than on ward rounds. We developed a corporate philosophy that we called 'The same team', as the goals of the providers and recipients of care were usually the same. We encouraged families to participate in planning and

delivery of care. 'The same team' also meant dressing the same, so the white coats disappeared.

Our mantra was taken from a paper by Dunstan [3]: "You should not judge. The success of intensive care is not to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored, the quality of the dying of those in whose interest it is to die and by the quality of relationships involved in each death". The process involved acquiring new skills in communication, particularly in listening. It required learning to understand others' ethnic, cultural, and religious beliefs. We learned that the deeper and closer relationships with patients and families meant their hurt and grief was shared. We learned that it was okay to show your feelings to others.

The process improved the relationships between all staff as well as between staff and patients. We began to attract the interest of our colleagues and were asked to see patients in the ward to assist with end-of-life care. The hospital changed from a 'Blue Card' system of identifying patients who were not for resuscitation to requiring a proper 'Do Not Resuscitate' order, which stated what treatment was to be withheld, what treatment was to be continued, why the decision had been reached, who was involved in making the decision, and why the patient was not involved (if they were not involved). Our hospital made 'Do Not Resuscitate' orders a quality issue: 80% of patients who die had such an order when the notes were last surveyed.

We began to be asked to present in other hospitals, and to lecture our new interns on dying, a subject we learned was not dealt with in undergraduate training. Eventually, with some trepidation, we produced three papers describing our activities, including the policy of not providing treatment that would not influence outcome at the request of patients or families [4–6]. The papers were taken up by the national press: 98% of the feedback was positive.

With the help of Joe Civetta's Withdrawing and Withholding Care Policy from Jackson Memorial Hospital in Florida, we developed a hospital policy on Withdrawing and Withholding Care. This policy went to the Health Department, who referred it to the Legal Section. Their response to the question 'Could somebody acting in accordance with this policy be charged with murder?' was affirmative. Laws were drafted, and were discussed at a public meeting involving a diverse range of groups, from The Right to Life to The Cryonic Preservation Society. It was a meeting I regard as very important and significant. All groups were unanimous in believing that end-of-life care was an inappropriate matter for laws, courts, and lawyers. Such matters should be resolved by doctors, patients, and families. The morass of case law regarding the ethics and practicalities of end-of-life care in the USA convinces me

that this was a very mature attitude for a representative group to take. The public of New South Wales wanted guidelines, not laws.

One member of the profession at the meeting put the question regarding a charge of murder to the legal expert in a different manner:

'Do you think it is likely that a doctor withdrawing life support from a patient in New South Wales would be prosecuted for murder?'

'If prosecuted, is it likely that a conviction would be entered?'

'If convicted, is it likely that other than a derisory sentence would be given?'

The answer to all three questions was 'No'.

The New South Wales Health Department Interim Guidelines for Withdrawing and Withholding Care were released in 1992. I suspect they were made 'interim' because of political fear that they may have caused controversy and cost votes. The reverse occurred. There were no dissenting voices from either ends of the spectrum. In two cases, the State Coroner accepted the guidelines as an appropriate standard of behaviour. The Health Department sought public comment. The final version, incorporating those comments, is due before the end of 2002.

The increased awareness of consumers, the diversity of families, and the confidence-breaking patients who threaten our ability to prognosticate by surviving well, against impossible odds, tend to make these processes more complicated today than they were when we first set out on this path. But there is no doubt that it made our intensive care unit a better and fairer place to work, and almost certainly made those of us who walked the path better doctors and nurses, and better human beings. We are constantly impressed by the wisdom and dignity of Australians from all ethnic, religious, cultural, and social backgrounds in dealing with end-of-life decision-making for those they love, when empowered to be part of the process.

There are studies suggesting to us that this approach may not be favoured in other areas. The SUPPORT investigators found that bringing patients' wishes to the notice of treating physicians did not improve the quality of end-of-life care [7]. In a more recent French study, the patient's family was involved in only 44% of cases [8]. We have no data that the process we have developed is better than any other. We have received two letters of complaint since 1982 related to withdrawal of care against the families' wishes, referred by the New South Wales Complaints Unit. No action against the doctor involved was deemed necessary. In contrast, we have a vast quantity of mail thanking us for the care and consideration shown.

In 1967, the art critic John Berger addressed the question 'What is a human life worth?'. His answer was: "I do not claim to know what a human life is worth – the question cannot be answered by word but only by action, by the active of a more human society" [9]. We believe there are enormous benefits to both consumers and deliverers of health care in the active creation of a more humane intensive care unit, and this is an appropriate area for our speciality to show leadership.

Competing interests

None declared.

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