Commentary

Medical treatment for the terminally ill: the 'risk of unacceptable badness'

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Published online: 10 May 2005
This article is online at http://ccforum.com/content/9/4/317
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Critical Care 2005, **9**:317-318 (DOI 10.1186/cc3715)

Abstract

When patients or their families rarely request inappropriate end of life care in the ICU for capricious reasons. End of life treatment decisions that only prolong discomfort and death are usually emotional and based on unrealistic expectations. I explore some of those reasons in this paper.

Recent times have witnessed much turmoil regarding the 'life is sacred at any cost' maxim [1]. Current technology is capable of indiscriminately maintaining some of the vital functions of the body, but the same technology does not necessarily allow us to heal underlying disease processes [2]. An unintended side effect of modern technological advances has been the plausibility of maintaining moribund patients in a state of suspended animation for prolonged and sometimes indefinite periods [3]. Also, advanced resuscitation techniques make it possible to convert death into life-in-death [4]. Patients may be stalled in suspended animation; they are not alive in the sense the we enjoy life but neither are they able to die as long as nutrition, hydration, ventilation, and perfusion are assured. In many cases reanimation of such patients is clearly impossible, even with the advanced medical technologies available to us.

This conundrum is created because we must be prepared to apply life-sustaining technology to patients when the benefit appears to outweigh the risk and when there is a reasonable chance for an outcome that the patient would desire. It frequently seems reasonable to buy sufficient time to see whether the disease will respond to aggressive treatment by instituting the most invasive life support technology. However, if organ system failure is not reversible, then the reasoning behind life support technology becomes moot. We must then be prepared to remove supportive technology when it appears that inevitable death is being delayed, rather than meaningful life prolonged [5].

The courts have repeatedly affirmed competent a patient's authority to regulate their medical treatment, regardless of their reasoning [6]. However, when the patient becomes incapacitated, family surrogates are granted authority to make decisions regarding treatment options because of their proximate knowledge of what the patient would have wanted before they became incompetent [7]. This position is based on the postulate that any attempt to interject physician paternalism into the surrogate decision-making equation is ethically unacceptable. Most rational surrogates are unwilling to continue life support after a reasonable trial has demonstrated that its benefit has passed the point of diminishing returns. However, there is a continuing trend of surrogates demanding that moribund patients be kept on life support after prevailing medical opinions concur that there is no meaningful chance of reanimation [8].

Some reasons why this occurs are as follows:

1. Physicians tell surrogates that they can make any decision they want as an open-ended ideal. This puts them in the position of being buyers in a consumer's market. By asking them to make a choice, they imply that their authority to make choices extends to making bad ones.
2. Moribund patients look comfortable on 'life support'. An observer's primal reaction to the vibrant external appearance of a body supported in an intensive care unit (ICU) is radically different from that to a corpse on a morgue slab [9]. As long as the patient 'looks viable, it is emotionally easier to accept the pie in the sky bye and bye long shot cure'. If the patient can just be maintained comfortably for long enough, then a cure may eventually become possible.
3. Surrogates dislike being in a position of making decisions that directly result in the death of a loved one. Once life-supporting care is instituted, the patient has options for 'survival' that they did not have before, even though they are dependent on 'life support'. There are now variables

ICU = intensive care unit.

that decision makers control, and it is much easier to avoid decisions that may hasten death [10]. Instead of yielding to inevitable death, the potential now exists to manipulate it. Life support generates an outcome that is no longer inevitably fatal.

4. Physicians do not have an exceptional track record in explaining end-of-life issues to patients and their families [11]. It is not uncommon for physicians to ask loaded questions in their quest for end-of-life decisions. For example, 'This is your grandmother's 17th transfer from a skilled nursing facility in 3 months for sepsis and respiratory failure, and now she's in kidney failure as well. What do you want to do: everything or let her die?' Given that choice, most surrogates would opt for doing something rather than nothing, even if 'something' perpetuated open-ended pain and discomfort.
5. The popular media, especially the tabloids, frequently feature anecdotal articles describing patients who have awakened after years of coma [12]. Most if not all of these patients' conditions have been embellished to generate public interest, and frequently subsequent investigators cannot find these patients. Accordingly, some families feel that if life support systems can maintain vital signs for a day or a week, then 'suspended animation' should be possible indefinitely, until a cure is found.
6. The notion of 'medical futility' as an end-stage process in which vital signs cannot be supported further is poorly understood by both physicians and surrogates [13]. In fact, any medical treatment capable of sustaining hemodynamics, ventilation, and metabolism is not technically futile if it achieves that limited goal [14]. A treatment is futile only if it is unsuccessful in achieving a stated goal. Therefore, if a patient in a progressive, inevitable death spiral is placed on mechanical ventilation, it is not technically futile if vital signs are sustained, however briefly. It is medically inappropriate but not technically futile. Under the current rules, the only test of futility is that embodied by the question, 'Will this treatment result in sustained life?' If the answer is 'yes', then virtually any treatment is fair game, even if it will do nothing to revitalize the patient.

Perhaps the most effective way of dealing with strong familial incentives to tread the path of least resistance in end-of-life care is twofold. First, in end-of-life issue discussions, we must strive for 'consensus without consent' [15]. Discussions with surrogates should strive for concordance and understanding but not extend to soliciting their consent for medically inappropriate care. They simply should not be offered inappropriate end-of-life care. Second, we should strive to emphasize what Streat and coworkers [15] termed, 'the large risk of unacceptable badness', rather than a vanishingly small potential for benefit.

There are far worse things than death, and many of them occur in ICUs when futility maxims are circumvented. There is a population of ICU patients who will die no matter what treatment is rendered them. Medically inappropriate care causes pain, suffering, and discomfort. The fundamental maxim for these patients should be comfort. Extraordinary life support for patients predicted to die does not equal comfort care.

Competing interests

The author(s) declare that they have no competing interests.

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