Avoiding nosocomial dysthanasia and promoting eleothanasia

“Doing no harm” includes a responsibility not to make dying miserable by means of medical treatment.

Intensive care treatment has a great ability to save life, to cure and to restore health. When used wisely, modern intensive care can greatly benefit critically ill patients.

However, it is also possible for even the most intensive intervention to fail to restore health. In this situation there is a very real chance that the intensive, invasive treatment delivered by the combined efforts of the treating team may serve only to prolong the person’s dying, and to invest his or her final days with pain, discomfort, loss of personal dignity, intrusive medical technology and the exclusion of family from the bedside while investigations, procedures and treatments are implemented.

The expertise to maintain life with mechanical ventilation, dialysis and cardiac support has developed within the past 40 years. In the early days, intensive care was limited to young patients, and elderly patients were rarely admitted.

Over recent years, much has changed. Many patients admitted to intensive care are now much older and much sicker than in earlier times. In many cases, these frail and failing patients might realistically be considered to be well into the process of dying — and very close to the end of their natural lives.

Most elderly patients report that they are willing to “accept” a short period of intensive treatment to treat easily reversible conditions,1 but recognise and accept the inevitability of death.2 The father of one of the authors reflected this attitude when he said:

At eighty-six, death shouldn’t be a big surprise. I am expecting it. I’m not looking forward to it, but I hope to only do it once and to get it over quickly.

Indeed, patients consider a “good death” to include good symptom management, avoiding prolongation of dying, achieving a sense of control, relieving burdens placed on the family and strengthening relationships.3 Very few elderly patients express a desire for prolonged, intensive treatment,4 but medical and surgical specialists who make referrals to the intensive care unit will frequently not accept the inevitable death of their patients before prolonged intensive treatment has been tried and failed.5 Families often take a similar view: saving life “at all costs” is generally their goal, to “do everything” is the call, to “not let them go” is the plea. A request to be cautious, and to take care not to use medical treatment that simply delays and complicates an inevitable death, is unusual. Thus, an aggressive technological approach to final illness is common and invokes a period of intense and escalating medical intervention at the end of life for many patients.

While familiar with the term euthanasia (meaning good or comfortable death), it is interesting that we have no English word to express the concept of inappropriate, burdensome prolongation of dying by the unwise use of medical technology. When societies have no name for something, they are less likely to reflect upon or discuss the topic. A failure to name a situation and, consequently, to define, debate or consider it has dire consequences on society’s ability to deliver possible improvements. This is why we wish to introduce two new words into our vocabulary so that the intensive care community will start talking about these problems in a specific shorthand way. We hope that such initial use will then move to a wider medical discourse and, ultimately, to discussion in the wider community.

The first term we wish to introduce is dysthanasia. The word combines the Greek prefix “dys-” (meaning bad or difficult), which is widely used in the medical lexicon to indicate failure of things to occur in a desirable way (eg, dysfunction, dysarthria, dysphagia, dysphoria), and “-thanasia” (meaning dying, from Thanatos, the Greek deity for death). The word has only occasionally been used in medical papers and does not appear in the Oxford Dictionary. However, the term dysthanasia should be easily understood by doctors and the public and appropriately describes the problems we often see in dying patients in the ICU. Dysthanasia embraces the concept of an uncomfortable, unpleasant, medicalised death — a “bad” death.

It is now reasonable to wonder whether, in our desire to thwart death, we are regularly causing a hospital-induced (nosocomial) dysthanasia. This merits concern as it is contrary to what patients state that they desire5 and what we, as doctors, would wish for our patients — and indeed for ourselves and our own family members at the end of life. Because patients are typically unable to communicate the extent of their suffering, families and physicians who do not themselves feel the discomfort of chest tubes, indwelling catheters, endotracheal tubes, constant stimulation, sleep deprivation and the indignity of faecal incontinence, often inappropriately discount the “human price” of dysthanasia.

Finally, while acute dysthanasia is found in the ICU and in the wards, chronic dysthanasia occurs in the hospital or

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nursing home among profoundly disabled survivors of aggressive treatment. In our opinion, the issue of nosocomial dysthanasia needs urgent debate at a professional and societal level.

We also believe that the appropriate response to dysthanasia is the promotion of the opposing, positive concept of eleothanasia. Eleothanasia (meaning merciful death) is derived from Eleos (Ελεος), the Greek divinity of Mercy. Eleos was revered by the Athenians as the personification or spirit of mercy, pity and compassion, who assisted mortals facing the trials of life. Linking compassion and dying into one word (eleothanasia) could express the alternative to dysthanasia. Eleothanasia is what we should strive to achieve for our patients as death approaches.

The term euthanasia, in its current use, represents an illegal approach that offers no solution to the dying patient, particularly in cases where high-technology life support is actively preventing death. Euthanasia has multiple connotations, with polarised views of the morality of this approach. Furthermore, the term does not help the discussion, indeed it is deliberately used by some to confuse and limit useful debate.

Dysthanasia is the result of treating “at all costs”, without careful assessment and reflection. It can only be prevented or avoided if a conscious effort is made to critically assess, at regular intervals, whether the goals of treatment are achievable. If both doctors and families were to recognise the possibility of dysthanasia, in the setting of ineffective and burdensome attempts at cure, and acknowledge the value of avoiding it, then its incidence could be reduced. Once a term exists, operative definitions could be developed, diagnostic criteria applied, epidemiological studies conducted and its impact understood. At the same time, the named concept, eleothanasia, would be seen as an important and worthwhile goal.

In conclusion, we believe that new terms defining bad death (dysthanasia) and compassionate death (eleothanasia) may help clinicians and the public to increase their awareness of the issues surrounding dying in ICUs and hospitals. Giving names to both the problem and the solution could open up a field of investigation that may then lead to the development of preventive measures and effective interventions.

The need and the desire to deliver both dignity and freedom from suffering to our patients demand it.

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References