Defining limits in care of terminally ill patients

Despite what they might say, people at the end of life rarely want everything or nothing. **Ursula Braun and colleagues** explain how to understand and meet their needs

Invasive procedures in terminally ill patients often fail to change the course of disease.[1 2] Interventions can become inappropriate overtreatment if they result only in disease related and iatrogenic harm to the patient. Untimely referral to a hospice, poor technical performance, overuse of interventions inconsistent with preferences and prognosis, and poor communication,[3] increase the likelihood of inappropriate clinical intervention.

To facilitate appropriate care and avoid inappropriate interventions doctors need to anticipate discordance between their views and those of patients or surrogates, using the informed consent process to prevent potential discordance from becoming actual discordance and responding quickly when conflicts do occur.[4-6] It is imperative for good end of life decision making to identify, explain, and negotiate consensus therapeutic goals to ensure that appropriate treatment occurs. This process requires effective communication skills and cultural sensitivity. The clinical scenario below (which is fictitious but based on experience) illustrates the need for a proactive approach.

Clinical scenario

A 78 year old recently widowed man with non-small cell lung cancer and chronic obstructive pulmonary disease is admitted with pneumonia and impending respiratory failure for the third time within 10 months. His medical history includes congestive heart failure with an ejection fraction of 20%, a cerebrovascular infarct with mild cognitive impairment, and coronary artery disease. He has previously been difficult to wean from the ventilator and required a tracheostomy. During his last admission, he was finally weaned after 8 weeks. Afterwards, the patient told his wife and the team several times he never wanted to be on a ventilator again, but he did not complete an advance directive.

The doctor starts bilevel positive airway pressure, but intubation seems impossible to avoid. Because the patient is confused, his care is discussed with his son, who has not previously been involved. The son wants "everything" done for his father. The respiratory therapist and the house officer who have cared for the patient at former admissions recommend against intubation and suggest a do not resuscitate order based on the patient's previously stated wishes.

Implementing the doctor's role

The first step in preventing overtreatment of terminally ill patients is for both sides to collect and share information. Before doctors try to explain medically reasonable choices, they must listen to and focus on what the patient or family already understands about the patient's condition. Goold and colleagues have assembled some questions for doctors to use in this context, such as "Why have you decided to…?" "What are you hoping we can achieve?" "What do you think [the patient] would want us to accomplish for him/her?" They also encourage doctors to consider what words or phrases they may have used that might be contributing to the conflict—for example, "stopping treatment," "withdrawing care."[7]

Doctors should focus on knowledge about the disease course and its responsiveness to treatment. It is important to clarify the patient's and surrogate's expectations regarding outcomes, resolve misunderstandings, and correct unfounded expectations. Additionally, the patient or surrogate needs to understand the potential side effects of treatment and their prevalence. For example, when discussing cardiopulmonary resuscitation, it is important to explain that ribs may be broken, burns can occur, success is inversely proportional to length of resuscitation, and the likelihood of returning to the former level of functioning may be small. Both short and long term outcomes must be explained. Doctors should make clear that good medical care does not always mean doing everything that is technically possible; in fact, sometimes what is technically possible is clinically inappropriate.

Doctors need to identify what is important to the patient, including any religious beliefs.[8] If the patient cannot respond, the doctor must determine from the surrogate what the patient's values and goals might be—the substituted judgment standard.[9] Doctors need to remind surrogates that their decisions should be based as much as possible on what the surrogate thinks the patient would want, rather than on what the surrogate wants.

Finally, doctors should, after acknowledging the situation's difficulty, present their expert opinions and not shy away from making recommendations because of a misplaced fear of upsetting the patient or surrogate.[10] A surrogate may appreciate such recommendations because they can reduce guilt and the feeling of being solely responsible for the outcome.

A good death

In the late 18th century, the Scottish physician-ethicist John Gregory called for doctors to "smoothe the avenues of death."[11] In contemporary terms, this means that doctors should focus care on securing

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effective palliation and helping patients maintain their dignity. Doctors should clearly convey to patients and families that inappropriate treatment is not benign but almost always associated with appreciable burdens and little or no expected clinical benefit. The goal should be to convey that overtreatment can cause preventable suffering.

Responding to requests

Surrogates usually do not realise that a request for doing "everything" may lead to overtreatment. Simultaneously, doctors often do not take the time to clarify the nature of such requests. In the scenario described above, the son, having had no conversation with his father regarding his preferences for care, requests everything. To prevent a crisis in decision making, the doctor should immediately explore what "everything" means to the son and what he understands its consequences to be. The doctor should then provide an accurate, sensitively presented account of the predictable consequences of doing everything and follow up by exploring with the son how these consequences may not serve the shared goal of providing the best care.

Explaining that refusing to intubate is not equivalent to stopping treatment and detailing all the therapeutic options that will ensure his father's comfort will help the son to understand that good medical care will continue. Families need to understand that not doing "everything" is not equivalent to doing "nothing," which some might wrongly assume. The doctor should set realistic goals that focus on preventing inappropriate intervention, thereby ensuring comfort and maintaining dignity.[12]

Build consensus

The process of finding out what the patient or surrogate already knows or does not know, identifying expectations and misconceptions, and clarifying expectations should always return to what the patient's values and goals would be and why inappropriate intervention might not support these values. Identifying the most and the least likely outcomes helps both sides. In our scenario, the son had no knowledge of the extent of his father's disease, his prognosis, or the wishes made known to his mother and the care team. Occasionally, responding to a request for aggressive treatment with an offer of a limited trial of an intervention (such as, mechanical ventilation for a few days) may preserve control for the family, protect the patient from prolonged inappropriate intervention, and conserve the opportunity to reach consensus on ending such intervention.[8 13]

Document agreements

Once consensus has been reached, it is important to document the discussion in the patient's notes and to write appropriate orders immediately. Failure to promptly document the decision in the record can lead to overtreatment by default and harmful treatment. For example, both the house officer and the respiratory therapist knew of the patient's desire not to be put on the breathing machine again. However, they failed to document it. Since the patient's wife knew of his preferences, the doctors also should have encouraged her to discuss his wishes with other family members.


HENNY ALLIS/SPL

Care should be focused on maintaining the patient's dignity and supplying effective palliation

Planned discharge

Many patients who have a do not resuscitate order leave the hospital alive. Discharge planning is a crucial but underused tool to prevent inappropriate treatment. After being weaned from mechanical ventilation on his last admission, the patient should have been asked if he wanted a do not resuscitate order for future admissions and given the opportunity to complete an advance directive.

Additionally, in some US states patients can opt for do not resuscitate orders out of hospital. Failure to discuss and write such an order may lead to inappropriate resuscitation attempts. Other patients may benefit from orders not to be admitted to hospital—for example, patients with severe dementia whose quality of life may be severely diminished by hospital admission. Proactively discussing such options with surrogates can prevent patients becoming agitated by the new environment, which could result in patients falling or danger to caregivers.

Discussion

When doctors offer all technically possible alternatives unedited by clinical judgment about which ones are clinically beneficial or simply acquiesce to requests to "do everything," they yield their proper role in the informed consent process.[10] This failure reflects a fundamental misunderstanding of the doctor's professional role in the informed consent process. It does not violate the terminally ill patient's or a surrogate's autonomy to recommend against clinically inappropriate interventions and provide an evidence based explanation that justifies the recommendation. A successful ethical approach requires doctors, guided by professional integrity, to exercise responsible influence over the informed consent process.[5 14]

A personal empathic approach to recommending against certain procedures may enhance trust and credibility. It can help surrogates manage feelings of guilt and reduce the burden of decision making. The doctor in our scenario could have advised the patient's son by saying something like: "This must be a difficult situation for you, especially since you were not able to discuss this with him. If your father were my dad, I would reject intubation."

Curative and palliative care should not be dichotomous. Doctors need training in palliative care and in integrating it into their practice.[15] Patients should not have to forgo curative treatments to have access to palliative care, nor should they have to forgo palliative care just because they are still undergoing curative treatment.

Earlier involvement of a palliative care approach, such as enrolment into a hospice, can facilitate subsequent transition to purely palliative care. Recommending palliative and hospice care is a seriously underused strategy for dealing with overtreatment of terminally ill patients.

Resolving conflict

The outcome of our opening scenario was that the house officer and the respiratory therapist who previously cared for the patient met with the son and discussed the goals for treatment. The son was informed of his father's previously stated wishes to avoid further intubations. The son was upset by seeing his father in respiratory distress. All agreed that the patient's comfort was most important. Morphine was started and a scopolamine patch applied. The patient died two days later with his son present.

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STEPS TO AVOID INAPPROPRIATE INTERVENTION

Listen, verify understanding, and offer choices with contextual risks and benefits

Focus care on maintaining the patient's dignity and supplying effective palliation

Respond to requests for intervention

Build consensus

Document agreement on an effective strategy for care and incorporate it in the care plan immediately

Plan the discharge and document decisions

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Are you addicted to your "crackberry"?

Hand held computers and portable email devices are routine in many walks of life, including medicine. These devices facilitate working from home or while in transit, allowing busy individuals never to be "out to lunch." However, they can also make it harder to achieve a healthy work-life balance, intruding into one's time away from work.

In view of concerns over behavioural addiction to these new technologies, with consequent negative impact on other aspects of life, I have devised a short screening test (based on the CAGE questionnaire for alcoholism) for pathological addiction to hand held devices:

- Do you get annoyed if you are asked to **S**top using your hand held device?
- Do you take your hand held device on **H**oliday with you?
- Do you get **A**nxious if you cannot find your hand held device?
- Do you ever **M**isperceive a sound as the ring tone or call sign of your hand held device?

If you answer yes to all four of the SHAM questions, then you should consider taking a period of abstinence from your hand held device. Others around you may find a period of abstinence changes you for the better.

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