

Never say die?—as treatments fail doctors' words must not

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The problem of an inadequate end-of-life care for hospitalised patients not specifically receiving focused palliative care is common, but avoidable. Existing healthcare systems and personnel can and should provide excellent care at the end of life to patients dying in hospital. That they do not is an avoidable tragedy, as hospice care and the philosophy surrounding this approach to dying patients use similar resources and provide exemplary treatment at the end of life.

Introduction

Language is the most important tool that clinicians and other healthcare workers in hospitals have at their disposal for making improvements in the care of patients dying. (This contrasts sharply with the ability of technology to improve survival and function.) In this essay, I will discuss how language, often used unconsciously by physicians and other healthcare workers, contributes to the unbalanced care patients frequently receive at the end of life, and offer words that help prepare patients, families and their caregivers for death and dying. A summary of common linguistic problems and some alternatives is presented in Figure 1.

Never say die

Failing to talk openly about death and dying with patients and their families is widespread (1). This 'never say die' position is venerated and embedded in medical culture (2). Despite death being a likely or certain outcome, patients and their families may hear that the prognosis is poor, that the patient is seriously ill, that the disease is progressing, or that the patient is 'failing to respond.' They often do not hear that the patient is dying or likely to die. They should. Physicians must first ask themselves if a patient is likely to die in the near future or coming to the end of his or her natural life, and whether or not their colleagues would agree. If the answer to these questions is clearly 'yes', then patients and their family members must be told as much.

Collusion in communication about death occurs even when the underlying illness is a fatal cancer (3); however, waiting for patients or their family members to initiate discussion about death and dying is

ineffective in the face of denial and unnecessary when acceptance is forthcoming. Asking permission to talk about prognosis can facilitate discussion while respecting individual patient autonomy.

Informed consent for death?

The General Medicine Council in the United Kingdom recently published guidelines stating that *terminally ill* patients should have their preferences, for cardiopulmonary resuscitation (CPR) routinely ascertained (4). (Emphasis added.) Many will prefer to forego such treatments; however, physicians and policy makers overlook at least four limitations arising from seeking consent to withhold treatments at the end of life. First, many patients do not know what they want and make a reflexive decision 'on the spot.' It is important to ask if patients have ever thought about the kinds of treatment they would want if they became seriously ill rather than assessing preferences for specific treatments initially. Secondly, assessing specific preferences provides 'de facto' proof that the treatments in question are potentially effective – why else would they be discussed? Thus, the process encourages false hope. Thirdly, when dying patients choose to receive treatments such as CPR, challenging this decision demonstrates that preferences are elicited but not respected, decreasing trust when it is most needed. (Linguistic abuse continues when patients are said to be 'demanding' treatments that were in fact offered.) Fourthly, efforts to obtain consent to withhold life-sustaining treatments that clearly are not going to work, such as CPR, can reduce the process of shared decision-making near the end of life to simply obtaining a 'DNR' order.

Physicians must ask if treatments could be effective; if they would not be and this decision would be supported by medical opinion, then treatments such as CPR could be presented as ineffective (5). (This assessment does not stop patients or their family members from challenging it or demanding that treatments be provided.) Equally importantly, when sought, the preferences of the family and patient must be respected. When death is likely, this information must be clearly given. ('I am sorry; your

Improvements in end of life care depend upon the careful and considered use of language

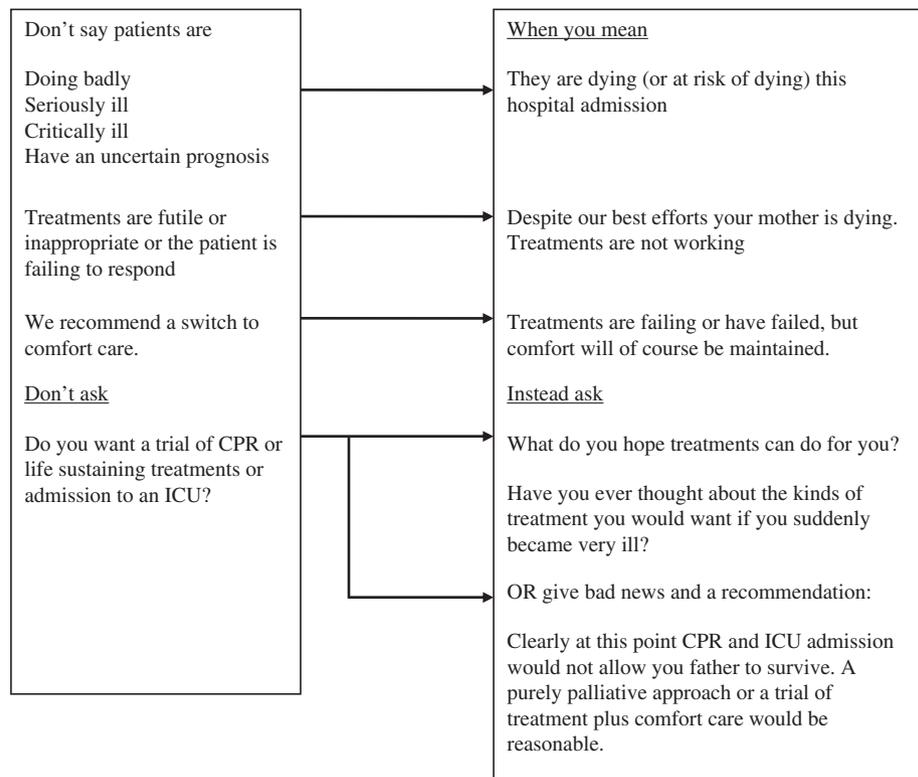


Figure 1 Euphemism free communication

father is likely to die no matter what treatments we decide on.) Tradeoffs may exist between comfort and cure (6) and these should be highlighted as is already done in hospice care settings. In many situations, a purely palliative approach should be presented as an option or the only option. Finally, prior to establishing decisions about specific treatments, patients' goals of care must be sought and identified such that treatment recommendations can be tailored to meet them. Establishing if survival or comfort, or both, is a priority, can be a useful starting point.

Communication of uncertainty

While many physicians do not like to communicate an uncertain prognosis (7), when uncertainty about life and death is openly communicated and shared, ideally in a responsive manner (8), living and caring can be enhanced and acceptance of the painful reality of impending death can exist and grow. 'It is possible you mother could die this admission,' or, carefully spoken, 'You could die this admission.' When this is true, physicians should strive, with care and compassion, to say as much.

Patients may have strong reactions to hearing they could die sooner than they expect or wish, but skillfully asking 'What are you most afraid of?' or 'Can you tell me what it is you find the most upsetting?' can

be of help. Functional magnetic resonance imaging studies suggest that expression of an emotion reduces its intensity (9). The worst suffering is felt in silence. Conversations about death and dying, like the physical examination (10), must have a sense of the sacred if they are to reach their full therapeutic potential.

When treatments fail

Treatments at or near the end of life are often described as futile or inappropriate. These words do not tell families and patients what physicians alone can and must at times communicate: that treatment will not keep the patient from dying. Instead, physicians can and should make a determination of non-effectiveness —'I am sorry, I wish I could give you some other news, but treatments will not or are not going to allow your son to survive this illness.' Acknowledging emotions and providing team-based emotionally supportive care at this time is essential. 'Switch to comfort care' is a phrase that should be banished from medical practice. ('We will of course *continue to maintain* his comfort and dignity to the best of our abilities.')

Paradoxically, conversations about death can be life affirming. I met an elderly man in an ICU whom I had cared for several years before, but his illness was so advanced that I did not recognise

him for several days. When I did, I slowly and painstakingly, at least for me, asked him what he would like to know about his condition. He looked right at me. 'I'd like to know just exactly what's what'. 'I, uhh, well, I think you are dying.' I hesitatingly replied. He fixed me with a broad white toothed grin and added enthusiastically; 'Well I do too!'

Disclosure

None.

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