A communication model for encouraging optimal care at the end of life for hospitalized patients

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Summary

Multiple studies have demonstrated that treatment at or near the end of life is rarely optimal. Unwanted death-prolonging treatments are frequently provided and open communication about death and dying is often lacking. Early effective communication about goals, prognosis and options would improve patient care at or near the end of life by enhancing choice and facilitating palliative care. A five-step sequential approach to communicating with patients at risk of dying in hospital about treatment goals and outcomes (and/or their family members) is presented. The steps are founded upon the recognition that trials of life-sustaining treatments are also, by definition, trials of palliative care. A narrative review of currently available qualitative and quantitative research is used to support the recommendations.

Introduction

Many people die in hospital often after a trial of life-sustaining treatments, including admission to intensive care, has failed. Such ‘aggressive’ treatment is often provided before prognosis and goals of care are determined even when the diagnosis is of an incurable malignancy, or a progressive and fatal disease such as congestive heart failure. Once initiated, trials of life-sustaining treatments can last days or weeks. The inability of physicians to exactly predict the time of death and a tendency to overestimate survival complicate decision making and promote overtreatment. One study demonstrated that on average the switch to comfort care occurred two weeks after admission and two days before death. Inadequate symptom control before death is also commonly described. Despite increasing public and professional awareness of these problems, the intensity, if not frequency of inpatient treatment before death in hospital is increasing in the United States.

Communication and decision making can be difficult during trials of treatment because illness frequently causes patients to lose decisional capacity. As well some patients will prefer not to discuss their prognosis. Living wills and advance care plans, while useful, are frequently not available or desired and do not obviate the need for communication. Consequently, physicians must very frequently help patients or their family members make ‘the transition from gravely ill and fighting death to terminally ill and seeking peace...’.

A network of medical ethicists in Canada’s largest urban center recently identified conflict over treatment decisions at the end of life as the most important ethical challenge facing society. In the United Kingdom, dissatisfaction with care at the end of life causes half of all complaints to the National Health Service. ‘In many cases,
families complained that they had received contradictory or confusing information from different staff caring for a relative. In other cases, relatives felt that they were unprepared for the death or had no time to arrange for family members to be present.25

Optimal care near the end of life requires effective communication. Although ‘end of life conversations need to become a routine structured intervention...’26 they are not. Nor are trials of communication strategies available. However current research can and should27 inform the communication process. In order to integrate current knowledge into practice, and as a stimulus to research and introspective practice, a five-step approach to communicating with patients and family members of seriously ill patients during a trial of life-sustaining treatments is proposed. A schematic outline of this approach is provided (Figure 1). For each step a structured dialog is presented in italics.

Step 1. Obtain informed consent for a trial of life-sustaining treatment

Physicians need to consciously consider28 and communicate that death is a possible or probable treatment outcome. When treatment is burdensome and potentially ineffective, patients should be offered the option of palliative care. Many are not.29–31 (Critical care nurses feel this failure is an important cause of over-treatment at the end of life.32) Failure to determine prognosis contributes to patients suffering unnecessary pain33 and receiving more treatments than they would have otherwise preferred.28,34–36

Whenever possible, patients need to participate in decision making as the ability of proxy decision makers to predict patient preferences is limited. Most patients will wish to participate,16,37 and many seriously ill patients believe that an open and honest relationship with their doctor was the single most important element of their care.38 Family members also prefer to know when death is a possible or certain outcome of treatment.38–41 Both treatment burden and likelihood of success should be established.42 Patients do not want physicians to defer advance care planning until the disease is very advanced43 and progressive illnesses may prevent patients from participating in future decision making.14

Acknowledging that treatment may fail can strengthen the relationship between family members and patients and health care providers,4,44 increase the emphasis on palliative and symptomatic treatment,4,45 and help create realistic expectations. Physicians should allow hope,46 but encourage realistic acceptance.

Discussions about prognosis are a good starting point as they frequently evolve to a discussion of treatment options.47 The extent to which treatment can help, and the expectations placed upon that treatment need be established.48,49 Family members or patients may identify circumstances under which treatment would not be wanted.50 Physicians must routinely address the emotional needs of both patients and family members. Carefully listening can be very beneficial to family members.51

Your father is very sick. Even with the very best treatment he might not survive. The only way to know if treatment will save his life is to try. At this time treatment would include... While treating him we would also ensure that he remains as comfortable as possible. We could also provide purely comfort care if this is what you believe he would want, although this means he would (probably) die. Have you ever talked about these kinds of things
with your father? How do you feel about what I have told you? Do you know what kind of treatment he would want?... Do you know if there are any reasons he would want us to stop these treatments?'

Step 2. When a patient’s prognosis worsens

When prognosis worsens, the goals of care should be reassessed. This can allow families and patients time to come to terms with the possibility of treatment failure. A stated willingness to continue to provide ‘aggressive’ treatments at this point helps demonstrate that everything possible is being done. At this point decisional authority clearly resides with patient and his or her family, however treatment recommendations and advice are appropriate.38,52,53

‘There is a small chance that treatment could allow you to survive. The chance of survival is getting smaller but it still remains at this time. I need your help to make sure that we give you treatments you would want to receive. Some patients would want treatment continued. Others would not. Do you know what you would like to do?... If you are uncertain my advice at this time is to continue for another few days and then reassess...’

Step 3. When life-sustaining treatment fail

Should ‘...[it become] apparent that further intervention will only prolong the final stages of the dying process’54 patients and family members should be told as much.55 Consistent prognostic information is strongly desired56 so medical teams and consultation services must obtain prognostic consensus whenever possible.57

Concluding23 and communicating58–60 that life-sustaining treatments have failed are difficult tasks and sometimes avoided.59 Assistance in communicating bad news, developed as part of the EPEC project, 6 (Educating physicians in end of life care) is available on the internet61 along with other sources.52 ‘Wishing’ that one could give better news is very likely true and worth stating.63

A shared understanding that treatment can only prolong the dying process must be established.57,64 Physicians trusted by the patients’ families may be of help in promoting acceptance.56 Other medical opinions, bioethics consultations23 and consulting clinicians experienced in end of life care45 can also facilitate acceptance. Clergy are very important to some families.59,65 Hope is mutable and has a spiritual as well as probabilistic dimension65 so physicians should never say that there is ‘no hope’. Instead they can acknowledge that medical treatments, in contrast to religious beliefs, can no longer sustain hope.

‘Can you explain to me what you have been told about your husband’s condition? I wish I had something else I could tell you, but our efforts have not worked. I wish our treatments could save his life, but they have not worked as we had hoped. Am I certain he is going to die? I cannot see anyway that our treatments could stop him from dying, I understand that you hope for a miraculous cure, but our treatments cannot make this occur.’

Step 4. Stopping death-prolonging treatments

The majority of patients do not want the final stages of the dying process prolonged,66 However, ‘The clinician encourages decision making about treatment withdrawal too soon without acknowledging the enormous emotional impact of the loss and without first understanding their [patients’ or family members’] view of the patient’s clinical situation, conflict often ensues’.52

The role patients or family members will play in the decision-making process must be considered.67,68 For example, asking family members of incompetent patients to determine the appropriateness of treatment69 seeks informed consent. The consent process, by definition gives decisional authority away and strongly implies that the option to continue treatments remains equally available.

At this point the treatments will only prolong the dying process. Do you know if he would want us to withdraw treatment at this point? [or not?] At this point I would recommend that we withdraw treatments over the next several days while ensuring that he experiences no discomfort or distress [but treatment will be continued if you prefer.]

If a willingness to continue treatments does not exist, a care plan that includes comfort measures and withdrawal of death-prolonging treatments can be presented. (Family members can still ask or demand that treatment be continued however.) A clear treatment recommendation may be appreciated.67 Health care personnel frequently approach decisions to limit treatment from different perspectives.70 They should reach agreement on a recommended care plan before talking to family members.

I wish I could give you some other news. I know how you have feared this possibility. We have done everything possible to allow your daughter
to survive. All I can do at this point is to allow her to die with as much comfort and dignity as possible and to help you deal with this terrible loss. We know patients do not want the dying process to be prolonged at this point, so if it is alright I would like to talk with you about what will happen next. Do you feel ready to do so? When patients are dying we withdraw treatments not necessary for comfort over a period of time.... How do you feel about what I have told you?...

Step 5. Requests for continued treatment

Some family members of unconscious and dying patients will want death-prolonging treatments continued. Respect for the sanctity of life demands that their reasoning be carefully and sensitively explored. Simply declaring that treatment is ‘futile’ forecloses further communication and is likely to be counterproductive.

Family members should be helped to articulate their hopes and fears and reasons for wanting continued treatment. Active listening, negotiation and compromise are all required. Ensuring patient comfort, minimizing conflict and distress, and taking efforts to maintain a working relationship with family members are important ongoing goals.

Disagreements about whether a patient’s quality of life justifies continuing treatment, as can occur for patients in a persistent vegetative state, can require policy guidance, third-party mediation, ethics consultations and external medical opinions. Conceding decisional authority to family members or patients will remove conflict but will not improve a poor relationship with health care providers.

’It helps to understand why you want these treatments continued. Can you tell me your reasons?...’ Since we cannot reach an agreement about the best course of treatment at this time, I would like to get some help for us. We have a policy at this institution to help us work through these disagreements. Until this disagreement is resolved we will continue to help support you, and continue treating and ensuring the comfort of your uncle.’

Potential benefits and limitations of adopting this approach

Currently there is a huge variation in treatment intensity patients in different hospitals receive at or near the end of life. The average terminal length of stay varied between 9 and 27 days between different academic hospitals in the United States, in some centers 36% of patients were admitted to a special care unit, while 9% were in others. The human and monetary costs of such treatment variation are immense. Given this level of variation in intensity of care, if the approach proposed decreases the use of death-prolonging treatments for hospitalized patients some potential benefits include:

1. Improved continuity: in an increasingly complex and fragmented health care environment, following and recording clearly delineated steps in decision making and communication would allow other members of the health care team to appreciate the stage of the decision-making process and allow family members to receive consistent information.
2. Enhanced patient autonomy and comfort: better communication and more emotionally supportive care would create an opportunity for patients and their family members to consider palliation as an earlier treatment goal. This could result in the earlier provision of end of life care and prevent unwanted or prolonged trials of life-sustaining treatments.
3. Earlier supportive interventions: early communication about death and dying, if done with tact and sensitivity, would help identify patients and family members who could benefit from education about the limits of modern medical treatments as well as earlier provision of psychosocial, spiritual and emotional support.
4. Decreased demands for treatment and conflict: supportively and incrementally helping family members to understand that death is unavoidable could help them accept treatment failure and decrease the chance that there would be sustained demands for life-sustaining treatments.
5. Improved outcomes and better use of resources are also possible. Neither survival nor satisfaction is necessarily improved with an increasing intensity of care. Paradoxically, in some areas increased expenditures resulted in slightly worse outcomes. Even a small decrease in intensity of treatment could have important resource implications since expenditures in the last year of life represent 20–25% of all Medicaid costs.

Limitations

The communication approach proposed in this article has not been validated and some studies cited are based upon outpatients. Clearly changes in practice would need to be adopted cautiously and incrementally by practicing clinicians. Finally, of course it is only likely to be effective when it enhances the personalized attentive care that patients and their families require at or near the end of life.
References


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