Decision Making at a Time of Crisis Near the End of Life

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THE PATIENT’S STORY
Ms J is a 54-year-old woman with metastatic breast cancer. Her medical oncologist, Dr B, had been providing oncologic care for 2 years; Ms J received multiple courses of chemotherapy and radiation for slowly progressive cancer. One week after starting a new chemotherapy regimen, she developed distended neck veins and had difficulty breathing. Dr B examined her as an outpatient, suspecting obstruction of the superior vena cava. Dr B discussed the range of diagnostic and treatment options with Ms J and her husband. He admitted Ms J to the hospital for a computed tomography (CT) scan and arranged for radiation therapy to begin that evening. Dr B later reviewed the CT scan, which revealed the expected superior vena cava obstruction, along with tumor compression of her trachea. Dr B met with the patient and her husband to discuss the new findings. Given the serious nature of her airway obstruction, Dr B discussed a new set of treatment options should she develop respiratory distress, including intensive care unit (ICU) admission and cardiopulmonary resuscitation. Based on this discussion, Ms J elected to continue the planned radiation therapy, to decline admission to the ICU if her symptoms worsened, and to execute an order to not attempt resuscitation or intubation. Within 12 hours of beginning treatment her symptoms improved; she was discharged home on the third hospital day.

Dr B was interviewed by a Perspectives editor in November 2003.

PERSPECTIVES

As patients approach the end of life, their disease process may create an immediate life-threatening emergency, yet invasive interventions may be less likely to provide benefit while carrying the same or greater risks. Knowing when it is time to shift from life-prolonging to more palliative approaches, focused on quality of life and comfort, is emotionally and clinically challenging for patients, families, and physicians. Key factors in the decision process include prognosis, risk-benefit analysis of the proposed intervention, current symptom burden, temporal pattern of the illness, patient’s age and life stage, and the patient’s goals of care. A structured approach to decision making includes assessing the patient’s physical, psychological, and spiritual needs; assessing the patient’s support system; discussing prognosis; and assessing patient-specific goals. Physicians can best help patients decide which treatments are appropriate by taking the necessary time to explore all curative and palliative care options, providing honest and timely prognostic information, making clear recommendations, facilitating patient-family discussions, and affirming patient choices.

JAMA. 2004;292:1738-1743

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DECISION POINTS IN A TERMINAL ILLNESS

The course of a terminal illness is typically marked by sudden worsening in the clinical condition between periods of relative stability. Such events can be asymptomatic (eg, new metastases detected by radiographic studies) or symptomatic (eg, aspiration pneumonia). In each case, the clinician, patient, family, or surrogate decision makers are confronted with deciding whether to pursue continued treatment aimed at prolonging life or instead to adopt an approach focused on specific end-of-life goals and comfort, with the recognition that death is approaching.

As medical technology has advanced, the dividing line between life-sustaining and palliative treatments has blurred. Current evidence suggests that physicians overuse technologically aggressive, life-prolonging treatments and underuse communication skills that can assist patients in choosing from a range of treatment options. In a study of 164 patients with advanced dementia and metastatic cancer admitted to a tertiary care teaching hospital, Ahronheim et al found that 47% of patients received aggressive nonpalliative treatments and that cardiopulmonary resuscitation was attempted in 24% of both groups of patients. Teno et al reported results from a family survey of 1578 patients who had died in a range of care sites. Compared with hospice care, patients dying in hospitals and other institutions had significant unmet needs concerning emotional support, physician communication, and symptom control.

Beyond the complexity of decision making based on medical facts is the enormous emotional burden these decisions carry. Physicians may view death as a personal failure and struggle with the issue of providing hope while trying to provide truthful information. Patients, families, or surrogates often experience feelings of guilt, anger, and loss at times when major decisions are required; thus, decision making is a challenge under the best of circumstances. Emotional reactions and the subsequent medical decisions are further influenced by the cultural and spiritual backgrounds of both the physician and the patient.

Clinical decisions that occur near the end of life fall into 2 broad categories: decisions to use potentially life-prolonging treatments for emergency conditions such as respiratory failure and decisions for situations that are non-emergent and typically involve the use of treatment modalities that emphasize quality of life. The BOX provides an outline of patient and disease characteristics that clinicians should consider in helping patients make informed decisions. Obvious factors include a treatment risk-benefit analysis and a clear, mutual understanding of the prognosis of the underlying illness. Less obvious factors include the treatment burden to families (eg, time off from work), the patients’ life-stage, and the temporal pattern of the illness.

The nature of the terminal disease, often divided into cancer vs noncancer, will affect decision making. The pattern of rapid functional decline that occurs in the last 3 months of life for most cancer patients is generally recognized by both patients and healthcare providers as the beginning of the dying process. Thus, discussions regarding the appropriateness of various treatment options during this time are held with the recognition that death is approaching. In contrast, there is no clear dividing line for most noncancer diseases, for which the functional decline is often protracted across years. Patients, their families, and physicians are more likely to have difficulty recognizing when such a patient is dying, and by implication, when further disease modifying therapies should be abandoned. This paradox is reflected in the relative paucity of noncancer admissions to hospice programs and the frequent admissions to ICUs for patients with end-stage chronic diseases.

The patient’s end-of-life goals at the time of decision making are also critical factors. Patients who are at peace with the notion that death is approaching or those who have no specific goals left to accomplish (eg, attend a family wedding) will commonly decline further interventions aimed at life prolongation. In contrast, patients with a strong sense of hope for future improvement or those with a strong denial of impending death are likely to seek out additional life-prolonging treatment options.

The patient’s psychological state can affect decision making. An important physician skill is to distinguish clinical depression from the normal grief and sadness associated with the dying process. Validated depression screening tools can be helpful. Chochinov et al demonstrated that using a single question, “Are you depressed?” correctly identified patients with depression in a sample of 24 cancer patients;
this single question performed better than the Beck Depression Inventory or depression visual analog scale. Indicators for psychiatric referral and treatment strategies have been reviewed in this series and elsewhere.17,20

Finally, physicians must be aware of how decisions are made, and by whom, within the patient’s family system, an issue that includes understanding the patient’s culture and spiritual belief system.21

ORGANIZING AN APPROACH TO END-OF-LIFE DECISION MAKING

Physicians can organize their approach to helping patients to make critical end-of-life decisions by assessing the patient’s current physical symptoms and psychological and spiritual needs, assessing family and social support system, estimating and communicating prognosis, and asking the patient to define his or her end-of-life goals.22,23 The optimal timing for this discussion is during a routine outpatient visit for a patient with any chronic life-limiting disease. The patient should have an opportunity to learn from the physician the future expected disease course, potential treatment options, and together with the physician, define specific goals of care prior to an acute medical crisis. This type of discussion may or may not result in a change from continued treatments designed to prolong life, and patients with noncancer diseases may be less willing to accept the finality of their illness. Furthermore, as Ms J’s case illustrates, not every crisis or possible intervention can be anticipated and discussed before the event. However, beginning the conversation can develop the physician's understanding of the patient’s preferences, reassure the patient that the physician is open to discussing end-of-life care, and begin what may be a slow process toward acceptance of a terminal diagnosis.

PHYSICIAN FACTORS THAT INFLUENCE END-OF-LIFE DECISIONS

Physician factors can influence end-of-life decisions, including the physician’s culture, spiritual beliefs, and personal values.24-26 These issues can transcend medical knowledge or currently accepted bioethical and legal principles. For example, some physicians feel uncomfortable with the concept of withdrawing or withholding artificial feeding near the end of life, fearing that patients will die a painful death, a belief not supported by research findings. In a study in which artificial nutrition and hydration was not initiated for 32 dying cancer patients, McCann et al27 found that symptoms of hunger, thirst, and dry mouth were uncommon and could be easily palliated with small amounts of oral food and use of ice chips.

Ideally, physicians should be able to provide accurate information concerning the range of treatment options in such a manner that their personal biases do not influence decision making while still allowing the patient hope. However, physicians often offer a better prognosis than they believe to be the case,28 and patient characteristics may affect communication. Lamont and Christakis29 performed a prospective cohort study examining physicians’ prognostic abilities among cancer patients in community hospice programs. Physicians reported that even if patients asked for prognostic information, they would only provide frank estimates 37% of the time. Cooper-Patrick et al30 completed a telephone survey of 1816 adults from primary care practices and found that blacks rated their visits with physicians as less participatory than did whites, suggesting racial differences within the physician-patient relationship. In a meta-analysis of 29 studies, Roter et al31 found that women physicians spent more time with patients, on average 2 minutes per visit; engaged in more active partnership behaviors; and provided psychosocial counseling. Other factors that anecdotally affect decision making include physicians’ feelings that arise in the face of their patient’s progressive terminal illness: inadequacy (“I don’t know what else to do.”); guilt (“I should have been able to do more.”); and family, patient, or peer pressure (“What will my colleagues think of me if I don’t keep fighting?”).

FIRST STEPS IN DECISION MAKING

DR B: The first decision point was in my office, when all I knew was that she had SVC [superior vena cava] syndrome. I told the patient, “This is what you have, and this is what it means—you can die from this really quickly if we don’t do the following treatments.” The next thing was explaining to her the various treatment options, including not to do anything at all. She indicated that all measures, including the most aggressive measure, would be appropriate because she wanted to continue to fight.

Several features of Dr B’s approach warrant discussion. First, the physician appropriately recognized the urgency of the situation. Second, Dr B allowed sufficient time to explore treatment options and to understand the patient’s values and goals. Although it would have been easier to say, “You need to go to the hospital for radiation or you may die,” Dr B detailed various options, including no antineoplastic treatment and allowed the patient an opportunity to express her goals.

The phrasing with which Dr B presented the third treatment option of not doing anything at all can lead to misunderstanding. Dr B was undoubtedly referring to the option of not using antineoplastic treatment. However, the patient may have interpreted this as meaning that nothing would or could be done to relieve shortness of breath and, by extension, that death would occur by suffocation. Patients need reassurance that no matter what treatment option is chosen, the goal of comfort will always be paramount: “A final option is not to use any further treatments to slow down or shrink the cancer but to refocus our efforts to ensure that you are comfortable for whatever time remains.” Without a clear description of pharmacological and nonpharmacological options for the control of
dyspnea, as an alternative to more invasive options, the over-
whelmed patient cannot truly make an informed deci-
sion.³⁰ Techniques, including sample phrases for end-of-
life goal setting discussions, have been published.⁸,¹⁶,³¹-³⁵

In the midst of making urgent decisions, assessing and
conveying prognosis becomes especially important. Physi-
cians are often reluctant to provide specific information about
prognosis, largely out of fear of destroying hope, so in-
formation provided is often overly optimistic.²⁵,³⁶-³⁹ Yet, prog-
nostic information is often the single most important piece
of information that patients need to make informed choices.
Physicians who actually know, but obfuscate by saying, “Only
God can tell” or “There is no way to know for sure,” may
not be meeting the needs of patients. In a study of 1032 can-
cer patients undergoing palliative treatments, 84.9% ex-
pressed a desire for as much information as possible, good
or bad. 7.3% wanted only good news, and 7.8% did not want
any details.⁸ Degner et al,⁴⁰ reporting results from a cross-
sectional survey of 1012 women with breast cancer, found
that 1 of the 2 most highly ranked types of information de-
sired from physicians was information about the spread of
disease. Finally, Gerle et al⁴¹ reported more than 40 years
ago that of 101 patients in Sweden with inoperable cancer,
the highest rates of anxiety and depression were found among
patients who were not told the truth of their condition.

Although destroying hope is feared by physicians, few data
support the notion that providing truthful information will
destroy hope.⁵ Loprinzi et al,⁴² discussing how to respond
to patient queries about prognosis, wrote, “Hope should not
be static. It should be a dynamic entity that is reframed by
circumstance, relationships, and the ongoing develop-
ment of one’s personal world view.” In other words, dying pa-
tients can still have hope for symptom control, of resolving
personal goals and values. However, many patients and fami-
lies struggle and ask such questions as, “Doctor, what would
you do if this were your mother?” The manner in which phy-
sicians respond to this query is part of the art of medicine.
Some will reflect the question back to the patient, “I really
don’t know what I would do if this were my mother, but
based on what I know of your condition and your goals, I
would recommend . . .” Other physicians feel comfortable
personalizing the recommendation, “If this were my mother,
I would recommend . . .” Quill and Brody⁴⁴ have suggested
that it is important for physicians to make clear recom-
mandations using a relationship-centered decision-making ap-
proach. They argue that the past 20 years have seen an in-
crease in patient-centered decision making, in which patients
are asked to make decisions without physician recommenda-
tions. They say that this process represents a limited un-
derstanding of the concept of patient autonomy and pro-
vides insufficient assistance to patients in navigating the
complex medical environment. In Quill and Brody’s rela-
tionship-centered approach, physicians are urged to con-
sider both the patient’s and the physician’s values and make
recommendations based on both.

MODIFYING THE PLAN:
PRESENTING CRITICAL INFORMATION

DR B: Following her first treatment, I went back to the patient
with the new information from the CT scan about her airway
obstruction. We now had to have an immediate conversation about
the various treatment modalities for airway obstruction, up to
and including intubation and mechanical ventilation. If radia-
tion produced temporary swelling, if radiation didn’t work and/or
she had respiratory failure from an airway obstruction, what
should be the plan? During that discussion, she decided not to
be intubated, and I supported her 100 percent. We decided to
 Supplement her with as much oxygen as we could on the ward,
but we would not take her to an intensive care unit or intubate
her. Her husband had more difficulty with this decision, but af-
after the 3 of us discussed it even more, he understood why.

For Ms J, the new finding of tracheal obstruction necessi-
tated a quick reevaluation of goals and treatment op-
tions. Once again, Dr B recognized the gravity of the situ-
aton and spent the necessary time to discuss treatment
options and end-of-life goals. The new discussion included
the options surrounding ICU admission and contingency
planning for managing the moment of death, that is, whether
or not to perform cardiopulmonary resuscitation. Dr B em-
phasized the treatments that could be used to alleviate dis-
tress, such as oxygen and opioids.³⁰

Deciding about ICU admissions, do not attempt resusci-
tation orders, and use of artificial hydration and feeding are
among the most challenging discussions in medical prac-
tice. The notion of dying may be viewed as an abstract con-
cept early in the course of a chronic illness. However, there
is no avoiding the reality of death during discussions of ICU
admission or withdrawal of artificial feeding. For many pa-
tients and families, deciding to decline further medical in-
terventions represents a relief, a letting go of what has been
a long struggle for continued life.³⁵ However, for others, their
families and, all too often, their physicians, the decision to
forego further life-sustaining measures, even in the face of
overwhelming evidence of imminent death, is viewed as giv-
ing up.³⁶ Guilt, “I should keep fighting”; anger, “Why didn’t
I go to the doctor sooner?”; shame, “My family will think I
am not a fighter”; and fear, “What will happen to me?” are
common responses in such situations. Assistance from pal-
liative care specialists, nurses, chaplains, psychologists, and
social workers can be especially useful.³⁷³¹

NEGOTIATING FAMILY CONFLICTS

The patient-husband dynamic described in this case is very
familiar to most physicians. The patient was ready to ac-
cept defined limitations in future care while the husband,
initially, was not. Acceptance of impending death occurs for different people at different times. A truism of palliative care is that dying patients usually know when they are dying and that acceptance of impending death is typically hardest not for the patient, but, rather, for those individuals whose lives intersect with the patient through strong personal connections. Provided the patient consents, the physician can assist the family and other individuals struggling to accept the impending death by including them as active participants in end-of-life discussions with the patient. In this venue, the patient is encouraged to express his or her feelings, concerns, and goals for end-of-life care. The physician’s role is crucial in helping facilitate these discussions in a manner that empowers patients to openly express their feelings and desires. Although nurses, social workers, chaplains, and others can help in this process, the physician’s role in providing emotional support, education, and affirming decisions is crucial.

ELICITING FURTHER PATIENT GOALS

The outcome of many goal-setting meetings is a decision to forego further life-prolonging treatments and to focus solely on comfort. At such a time it is important for all physicians and other health professionals to demonstrate their support: “I want you to know that I fully support your decision and will do my best to honor your wishes.” Once the overall goal has been established, an assessment of patient-specific goals can be made by asking, “What do you need or want to do in the time you have left?” Common replies include ensuring physical comfort, being at home with family, or attending an important family event. Physicians can help patients meet these goals by reviewing the current medications, tests, and interventions and for each to ask themselves, “Is this contributing to comfort; is this helping the patient achieve their goals?” Any elements not contributing to the patient’s goals should be discontinued. Research data from Finucane et al.,39 McCann et al.,27 and others reviewed elsewhere have demonstrated the lack of benefit and potential harm from continuing artificial nutrition or hydration for those with advanced dementia or near the end of life. For other common interventions, such as continuous pulse oximetry, prophylactic antithrombotic treatments, and parenteral antibiotics, there are few specific data to guide physicians in deciding which treatments should or should not be discontinued; when in doubt, combining patient-defined goals with common sense must suffice.

A final set of questions that can be addressed, once the goals of care become clear, concerns the place of end-of-life care and necessary support for the patient and family. Many, but not all, patients prefer to die at home. Among 246 community-dwelling persons older than 65 years with congestive heart failure, chronic obstructive pulmonary disease, or recent pneumonia, 43% expressed the desire to die at home. The Medicare Hospice Benefit is designed to assist families to care for their dying family member at home by providing nursing, social work, chaplain, volunteer, and physician services. Eligibility requirements for the Medicare benefit include a physician-certified prognosis of less than 6 months, assuming that the disease follows the usual course, and that the goals of care are palliative, rather than curative. Most private insurers now have a hospice benefit with some or all of the features of the Medicare benefit. Physicians can assist patients and families to accept the concept of hospice care by saying: “We have discussed your goals for the time you have left. To best meet these goals, I am recommending that you enroll in a hospice program.”

Management of patients who approach physicians specifically with a request to withdraw life-prolonging treatments, particularly patients whose deaths are not imminent such as those receiving chronic kidney dialysis, present a different set of issues. Physicians may be concerned that such requests arise from coercion of family members or represent treatable depression or delirium. Jenkins and Bruera have suggested assessment and management guidelines based on their experiences as palliative care clinicians; these guidelines conform to modern ethical principles concerning patient autonomy and decision-making capacity, blended with important principles of palliative care including thorough patient assessment and treatment to ensure maximal symptom control.

KEEPING FOCUSED ON THE GOAL

DR B: There are many things that I found helpful in this woman’s case that reminded me of key areas that make decision making in palliative care emergencies so challenging. First, it was important to give her accurate information as quickly as possible. Second, I felt it was critical to explain the full range of potential outcomes, including the worst case scenario. Third, focusing on the patient’s goals is central to decision making.

Dr B summarizes the important aspects of decision making near the end of life. Information must be provided that is timely, honest, and focused around the patient’s goals. No laboratory test, clinical pathway, or computer algorithm will replace the central role of the physician in helping patients and families navigate an increasingly complex medical care system. Working as partners with patients and families to make difficult decisions requires in-depth medical knowledge, leadership, the ability to self-reflect, and outstanding communication skills. The challenge for today and the future is to ensure that all physicians acquire and demonstrate these attributes.

Funding/Support: The Perspectives on Care at the Close of Life section is made possible by a grant from the California HealthCare Foundation.

Others Sources: For a list of relevant Web sites, see the article on the JAMA Web site at http://www.jama.com.

REFERENCES

2. Approaching Death: Improving Care at the End of Life. Washington, DC: Com-
mittee on Care at the End of Life, Division of Health Care Services, Institute of Medicine, National Academy of Sciences; 1997.


RESOURCES

WEB SITES FOR EDUCATION

Project on Death in America-Library Catalog
http://library.soros.org/dbtw-wpd/library_pdia.htm
Holdings of the library of the Project on Death in America (PDIA) in New York, NY.

American Academy of Hospice and Palliative Medicine
http://www.aahpm.org/bookstore/index.html
The UNIPAC Series: Hospice and Palliative Care Training for Physicians: A Self-Study Program, is an 8-part series of self-instructional books covering physical and psychological symptoms, ethics, and legal aspects of end-of-life care.

The EPEC Project, Feinberg School of Medicine, Northwestern University
http://www.epec.net
Education on Palliative and End-of-Life Care (EPEC) is a comprehensive palliative care curriculum with training materials.

Fast Facts and Concepts
www.mcw.edu/pallmed
More than 115 one-page reviews of key palliative care clinical information points, designed for brief educational encounters, self-study, or handouts.

Harvard Medical School Program in Palliative Care Education and Practice
http://www.hms.harvard.edu/cdi/pallcare
Intensive learning experiences for physician and nurse educators who wish to increase their expertise in clinical practice and teaching.

Palliative Care for People with HIV/AIDS
http://depts.washington.edu/pallcare/training/index.html
A 6-module curriculum and teaching resource for medical educators offered by the Center for Palliative Care Education, Seattle, Wash, 2004.

Palliative Medicine Resources on the Internet
http://www.smbs.buffalo.edu/med/intmed/pall.html
Compiled by the University of Buffalo School of Medicine and Biomedical Sciences, clinical and educational Web links to published clinical and practice guidelines, reports, journal articles, and newsletters; family guides; and journal articles. Other online sources are listed.

CLINICAL CARE

Center to Advance Palliative Care
http://www.capc.org
A resource to increase the availability of quality palliative care services in hospitals and other health care settings for people with life-threatening illnesses, their families, and caregivers.

A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice

POSITION STATEMENTS

Improving Palliative Care for Cancer: Summary and Recommendations