



Helping Older Patients and Their Families Decide about End-of-Life Care

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Abstract

Three-fourths of those who die in America are 65 or older. In all but the cases where death is sudden and unexpected, decisions frequently must be made about whether to limit treatment. In this paper, we provide a framework and specific tools that may help physicians in talking to older patients and their family members about end-of-life care.

After briefly reviewing the demography of dying and methods of advance care planning, we propose a four-step process for deciding about end-of-life care:

1. Identifying patient preferences.
2. Communicating about medical prognosis.
3. Defining goals of care.
4. Implementing a management plan consistent with those goals.

The paper concludes with special considerations about four common experiences of dying as an older person: chronic diseases with acute exacerbations (e.g. congestive heart failure or chronic obstructive lung disease), cancer,

end stage dementia, and unexpected catastrophic decline.

Introduction

Three chronic diseases lead causes of death in persons over 65: malignancies, heart disease, and cerebrovascular disease. Chronic and acute lower respiratory diseases, diabetes, and Alzheimer's type dementia follow. In Missouri, as in other states, 76 percent of those who die are 65 or older. In the year 2000, there was 41,645 deaths in older Missourians.¹ Most died in hospitals (55 percent), more than a quarter in nursing homes, and a smaller number at home.

Since most older patients die with chronic illness, advance care planning is relevant and its goals important. The first goal is to ensure that when the patient has become incapable of decision-making, the clinical care is in keeping with his or her preferences. Next is to improve health care decisions by facilitating a shared process, allowing the proxy to represent the patient's interests, and to respond flexibly according to unforeseen clinical circumstances. Finally, advance care planning aspires to improve patient outcomes by

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decreasing the frequency of over- or under-treatment and reduce patient concerns about the burden on family members.²

Patient-centered medical decision making near the end-of-life includes four steps: identifying patient preferences, understanding and communicating the medical prognosis, defining goals of care, and implementing a management plan consistent with those goals.

Identifying Patient Preferences

While some patients may speak with their physician or family members about serious illness or death, most do not plan for it. A relatively small percentage prepare a written advance directive, but even if an advance directive has been created, the accepted standard for making proxy medical decisions is speaking from the perspective of the patient: "What would she want if she were able to decide?"

While the patient's wishes may not be definitely known, considering them not only shows respect for the patient, but frequently aids difficult discussions with proxies or families. A family member may be personally troubled making a decision that might shorten life, such as withholding a gastrostomy and feeding tube, but may feel more comfortable with that decision if considering whether the patient would want to be kept alive when severely incapacitated and unable to eat.

Missouri law supports both

creating a written living will and naming a health care proxy. The state's first living will legislation was passed in 1986. A living will is a person's written instructions for treatment, to be used if that person loses the ability to decide. The durable power of attorney for health care is a health care proxy, named in writing, to make decisions when the person no longer can. Missouri's 1991 statute also permits the withholding of artificial nutrition and hydration if that authority is given to the durable power of attorney for health care.

Living wills have several advantages. They extend patient self-determination and afford legal security for physicians. They may relieve patient anxiety about potential unwanted treatments. Hopefully, they promote physician-patient-family communication, reduce potential strife among family members, and increase physician confidence in decisions regarding withholding or withdrawing of care.

However, there are also disadvantages to living wills. Neither physicians nor patients are likely to bring up the topic for discussion. They may not be available when needed, or their whereabouts may be unknown. Furthermore, it is often difficult to know when they should be applied, which can result in inappropriate adding or withdrawal of care. Finally, a patient's wishes may change by the time the directive is brought into force.

The health care proxy or durable power of attorney for health care may

afford advantages over the living will alone. It can serve as an extension of the patient's autonomy without the need to account for all possible scenarios of dying. It formalizes our common sense approach to patient care by talking with a loved one or family member when the patient is unable, one whom the patient has chosen to best represent him or her. The health care proxy also reduces the number of people to whom the physician must respond.

Health care proxies also have limitations. The patient may not have fully discussed their wishes with the proxy. This person could have an ulterior motive, or more commonly, may not otherwise accurately anticipate or represent the patient's wishes. Finally, he or she may not be emotionally or intellectually up to the task of making difficult medical decisions about a loved one, or may demand medical treatment with no hope of benefit.

What are useful strategies for initiating these end-of-life discussions with our patients? Timothy Quill³ has divided these into urgent and routine indications. Urgent indications include imminent death, talk by the patient about wanting to die, inquiries about hospice or palliative care, recent hospitalization for severe progressive illness, severe suffering and poor prognosis. Routine indications include discussing prognosis, discussing treatment with a low



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probability of success, talking about hopes and fears, and the circumstance in which the physician would not be surprised if the patient died in six to twelve months. This last indication may be particularly helpful in dealing with the uncertain prognosis in many chronic conditions, such as congestive heart failure. Others have found the routine exam to be an opportune time to begin gathering information about the patient's end-of-life goals and values.

Understanding and Communicating the Medical Prognosis

In order for patients to be adequately informed about their medical condition near end-of-life, physicians must be able to understand and communicate the prognosis. Unfortunately, many studies show that we are not very good at either. A recent study of hospice patients and the physicians who referred them found that on average, physicians predicted patients would live over five times longer than they actually did. The better the doctor knew the patient, the more likely they were to err in prognosis.⁴ The Study to Understand Prognosis and Preferences for Outcome and Treatment (SUPPORT) trial showed that three days before death from congestive heart failure, 80 percent of

patients were given a prognosis of six or more months. Two days before death, 50 percent of patients

with chronic obstructive lung disease were predicted to have a six-month survival.⁵

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"For most patients, two fundamental facts ensure that the transition to death will remain difficult. First is the widespread and deeply held desire to not be dead . . . Second is medicine's [limited] ability to predict the future, and to give patients a precise, reliable prognosis about when death will come."⁶

However, it remains our responsibility to do our best in telling people what we know, what we have to offer in the treatment of their disease, and what we will do to help them if that disease-oriented treatment is unsuccessful or not indicated. Cohort studies and clinical trials involving older patients with chronic illness will increasingly form our prognostic judgments. For example, a recent study showed that patients with advanced dementia who are hospitalized for a hip fracture or pneumonia have a six-month mortality of over 50 percent.⁷

Defining Goals of Care

Familiar with our general discomfort in talking about dying, Quill calls end-of-life discussions with seriously ill patients addressing the "elephant in the room."³ He suggests representative questions to ask about goals of care:

- ◆ "Given the severity of your

illness, what is most important for you to achieve?"

- ◆ "How do you think about balancing quality of life with length of life in terms of your treatment?"
- ◆ "What are your most important hopes?"
- ◆ "What are your biggest fears?"

He also recommends asking these questions about values:

- ◆ "What makes life worth living for you?"
- ◆ "Would there be any circumstances under which you would find life not worth living?"
- ◆ "What do you consider your quality of life to be now?"
- ◆ "Have you seen or been with someone who had a particularly good death or a difficult death?"

Gillick and colleagues⁸ at the Hebrew Home for Aged in Boston have described five pathways for nursing home patients that could be applied to chronically ill patients at home. They prioritize goals of care for life prolongation, maintenance of physical and cognitive function, and comfort. For the "Intensive Pathway" life prolongation is the prime goal, with maintenance of physical and cognitive function second, and comfort third. This pathway would employ all medical procedures including cardio-pulmonary resuscitation (CPR) attempts, intubation, and intensive care unit (ICU) care. On the "Comprehensive Pathway," the prime goal is maintenance of physical and cognitive function, with life prolongation second



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and comfort third. Attempted CPR and ICU care would likely be excluded on the Comprehensive Pathway, because they are unlikely to prolong life and may result in loss of function.

The “Basic Pathway” still has maintenance of function first, but comfort is second, and life prolongation third. This translates into nursing home- based care or home care for all medical conditions and substitutes medical treatment for surgical treatment whenever possible. On the “Palliative Pathway,” the prime goal is comfort, with the other two goals secondary. This translates to nursing home- or home- based care exclusively, with diagnostic tests kept to a minimum. For “Comfort Only” patients, comfort is the only goal and all treatments should be directed at treating symptoms. Discussing comfort as a goal of care may help patients, families, and learners (students and residents) appreciate potential disadvantages of tests and treatments that at a different time of life might be considered more appropriate. For example, maintaining an intravenous line in a patient with underlying dementia with delirium may require the use of physical restraints.

Implementing a Management Plan Consistent with the Goals of Care

EPEC (Education for Physicians on End-of-life Care)⁹ defines an eight-step protocol in guiding the discussion of treatment preferences, particularly when considering the withholding or withdrawal a life-sustaining therapy:

1. *Be familiar with policies and statutes.*

Are there specific policies within hospitals or nursing homes that preclude certain medical decisions? Most states and facilities leave specific treatment decisions to the patient and physician, but you should make yourself aware of any exceptions before the need to know arises. Sometimes when facilities indicate an unwillingness to allow certain treatment to be withheld or withdrawn, this policy could be based on a misunderstanding of applicable regulations.

2. *Determine the appropriate setting for discussion.*

In the hospital, this might be a patient/family meeting when all relevant providers – physicians, nurses, social worker, and chaplain — might discuss shifting the goals of care from disease treatment to palliative care. A comfortable meeting room away from the bustle of patient-care activities is highly desirable.

3. *Ask the patient and family what they understand.*

Patients, their families, and members of the health care team all may have very different perceptions of the patient’s condition and prognosis. These must be addressed if a patient-centered plan is to be developed. Furthermore, for cultural or other reasons, specific discussions about

death and dying may not be acceptable to some (see “Cultural Sensitivity in End-of-Life Discussions” page 67). It is important to be aware of what participants want to know and who will make what decisions.

4. *Discuss general goals of care.*

Plans should be consistent with patient preferences and goals of care; new circumstances may require a reconsideration of whether comfort care has assumed a more prominent role compared to other goals.

5. *Establish the context of the discussion.*

Reviewing the course of the illness and range of treatment options, even if cure is not possible, may help frame the discussion for patients and families. Physicians often make the common misstatement, “Do you want us to do everything?” Unfortunately *everything* sometimes includes futile disease-oriented treatment and may even exclude important aspects of palliative care.

6. *Discuss specific treatment preference.*

Be as specific as possible. Use language that patients and family members will understand. Pause frequently to check for understanding, write things down, and be willing to clarify. Describe each possible



Helpful Websites

Patient education

ACP-ASIM End-of-Life Care Patient Education Project
www.acponline.org/ethics/patient_education.htm

AAFP

www.familydoctor.org

Click on "patient handouts" Hospice care in the nursing home
 End-of-life care: CPR Artificial hydration and nutrition
 Cancer: Palliative care
 Cancer: End-of-life issues for the caregiver

General resources

Coalition to Improve Care and Caring at End-of-life
www.lastacts.org

About advance care directives and samples

www.partnershipforcaring.org

Education for Physicians on End-of-life Care (EPEC)
www.epec.net. (Go to the Participant's Handbook)

Helpful Books

Lynn J, Harrold J.

Handbook for mortals: Guidance for people facing serious illness.
 New York: Oxford University Press; 1999.

Lynn J, Schuster JL.

Improving care for the end-of-life: A sourcebook for healthcare managers and clinicians.
 New York: Oxford University Press, 2000.

treatment (whether a life-sustaining procedure or a specific palliative measure) discuss the problem the treatment would address, what the treatment involves, what is likely to happen if the patient decides not to have the treatment, the benefits of the treatment, and the potential complications and burdens created by the treatment. The specifics may include no resuscitation attempts, refusal of surgical procedures or dialysis, and/or no future hospitalizations.



7. Respond to emotions.

Physicians should acknowledge

the anxiety and grief that may be associated with discussions of dying. During such emotionally charged discussions, the physician should pause frequently, assess the participants' feelings, and respond to those feelings. Where emotions are clearly evident, they can be addressed directly (e.g., "You seem to be very sad"), and questions about perceived feelings (e.g., "Are you feeling angry?") are a safe way to approach challenging reactions that are less obvious. Physicians should not hesitate to get assistance from pastoral counselors or other members of the health care team.

8. Establish a plan.

Seek to establish a plan that is well formulated and understood. This

may include transfer of setting of care, specific withholding or withdrawal of care, and deciding when to meet again.

Experiences of Dying

Each experience of death is unique. However a few chronic illness trajectories encompass a large number of dying older patients. We have selected four to discuss further.

The patient with chronic heart or lung disease who has frequent acute illness exacerbations.

The chronic nature of these diseases affords ample opportunity to review patient preferences and goals of care. Both require expert medical management and patient/caregiver collaboration to maintain maximum function.

Prognosis is especially difficult, since patients will typically exhibit several (possibly many) cycles of becoming acutely ill and at least partially recovering after intensive medical interventions. Their decline is not steady as is often the case with a dying cancer patient. The SUPPORT study showed death can come suddenly and unexpectedly to these patients.¹⁰

Continuing discussions are imperative. The patient who may have started on the Intensive Pathway, in which life prolongation is the prime goal, may over time decide that the primary focus should now be on function and comfort. Here interventions such as attempted CPR and intubation must be discussed early on – decisions about whether or not to hospitalize again become important as the goals of care shift.

Attention to managing symptoms such as dyspnea and fatigue eventually becomes more relevant than treating the underlying disease. Hospice referral may be appropriate, not only to provide symptom management, but to support at home or nursing home those who have decided not to go back to the hospital. In considering the possibility of hospice referral, asking whether death would be surprising within six months or a year may be useful to help deal with our own difficulties in prognostication, as well as with patients' reluctance to face that death may be near. Also, it may be helpful to give patients and families the opportunity to focus on specific measures to enhance comfort.

The patient with an incurable malignancy. Like the congestive heart failure patient (CHF) or the chronic obstructive pulmonary disease (COPD) patient, those with an incurable malignancy may retain cognitive capacity until the very end. Since cancer usually progresses slowly, this means that eliciting patient preferences along the way and regularly reviewing goals of care in the context of prognosis is crucially important. As with the chronic heart or lung disease patient, several physicians may be caring for the patient simultaneously. Older patients and family members may find the disease-oriented treatments confusing, so it is important that specialists collaborate with the primary care physician, who can coordinate care and facilitate communication.

Plans of care should include symptom management: the average cancer patient suffers from ten different symptoms during the course of their illness.¹¹ Dying with cancer is the model upon which the current Medicare hospice benefit is based. If referrals are made in a timely fashion, symptoms (as well as the social and spiritual needs of the patient and family members) can be addressed from a multidisciplinary perspective.

The patient with end stage dementia. Excluding diseases that can masquerade as dementia, all true dementias are progressive and inexorably result in cognitive decline, functional loss, and death. Pharmaceuticals (such as the cholinesterase inhibitors) designed to treat dementia, primarily Alzheimer's disease, may slow decline but don't stop it. Thus, it is crucially important to describe treatment preferences and name a health care proxy early in the disease. Since the disease has expected outcomes, preferences can be elicited early on about specific interventions, such as resuscitation attempts, hospitalization, treatment of infections, and artificial nutrition and hydration. However, most patients at present do not create advance directives while they are competent and are not represented by legally appointed guardians. In such cases family members typically are called upon to reach decisions about care. In discussing care with family members, it is particularly important to help them keep in mind the perspective of the patient as if he or she were able to decide.

Many patients with dementia eventually are admitted to nursing homes. Such patients might appropriately enter the palliative pathway. This translates into nursing home-based care exclusively, keeping diagnostic tests to a minimum. Hospitalization might appropriately be restricted to situations in which comfort would be compromised in the nursing home (e.g., in some cases of hip fracture). Cardiopulmonary resuscitation (CPR) is extremely unlikely to be of benefit,¹² and Finucane¹³ and Gillick¹⁴ have persuasively argued that tube feeding has limited value.

In end stage dementia, when the patient can no longer communicate, ambulate, or sustain adequate oral nutrition, comfort care might become the only goal. That is, pneumonia would be treated with oxygen, antipyretics, and morphine, but not antibiotics. In those with severe dementia who are hospitalized, Morrison and Siu have demonstrated very high six-month mortality.⁷ While some family members may feel that any care limitation is inappropriate even considering the patient's preferences, many others will welcome being approached by the physician about care limitations.

The patient with an unexpected catastrophic decline (e.g., stroke). Major trauma and other unexpected catastrophic illnesses also occur in older adults. Severe stroke is a good example, where



there are several issues. First, the extent of potential recovery may be unclear for several days or even weeks.

Therefore long-term decisions may need to be deferred for a period of time and some aggressive measures, such as mechanical ventilation or enteral tube feeding might need to be instituted with the understanding that they can be discontinued later. Setting time limits for reconsidering care is particularly important in this setting.

Second, particularly in the frail elderly, a catastrophic illness may be accompanied by multiple interacting organ failures. Consider a patient admitted from the nursing home with mild dementia, who then sustains a stroke with hemiparesis, developing aspiration pneumonia, delirium, and progressive renal insufficiency. Previously recorded advance care directives may not address such a situation. While the prognosis of each of this patient's problems individually may be good, together they create a significant risk for prolonged intensive care unit stay and inevitably worsening functional status.

All such catastrophic illnesses require close communication with key family members or the health care proxy if appointed. Circumstances can change quickly, and difficult treatment decisions may have to be made, including CPR attempts, intubation, parenteral or enteral nutrition, and even dialysis. Being clear that initiated care can later be withdrawn may be particularly helpful at such times.

Having a script to initiate CPR discussions can be helpful. (paraphrased from Quill):³

"If your mother was to die suddenly, that is, she stopped breathing or her heart stopped, we could try to revive her by using cardiopulmonary resuscitation (CPR). Are you familiar with CPR? Have you given

any thought as to whether she would want it? Given the severity of your mother's illness, CPR would likely be ineffective. I would recommend that we chose not to attempt it, but that we continue with all other potentially effective treatments. What do you think?"

This example is particularly notable for the physician stating his opinion and asking for input from family members. We believe that in most circumstances it is cruel to simply pose choices to family members without the physician stating his or her opinion and then asking for input. Family members should not be placed in the position of feeling that *they* have to choose between death or an unproductive life for their loved one.

Conclusion

Unquestionably there are barriers to discussing end-of-life care with families and patients. Uncertain prognosis and slow decline may leave optimum decision points unclear. Physicians may be uncomfortable with potentially difficult and time-consuming discussions. Nonetheless, it is usually beneficial to address these issues before a crisis in which treatment decisions must be made quickly.

Physicians can do a great deal to help elderly patients and their family members make decisions regarding end-of-life care. Most people who die are old, and most old people will die of chronic diseases. This points to the importance of advance care planning. A four-step process to achieving patient centered decision making about end-of-life issues includes: eliciting patient preferences, determining and communicating about prognosis, defining goals of care, and implementing a management plan consistent with the goals of care. Physicians and family members who achieve these goals can acknowledge a

good death - the loss of a valued person who died comfortably, their physical, emotional and spiritual needs being fulfilled.

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