

## Special Communication

# Communication About Serious Illness Care Goals

## A Review and Synthesis of Best Practices

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An understanding of patients' care goals in the context of a serious illness is an essential element of high-quality care, allowing clinicians to align the care provided with what is most important to the patient. Early discussions about goals of care are associated with better quality of life, reduced use of nonbeneficial medical care near death, enhanced goal-consistent care, positive family outcomes, and reduced costs. Existing evidence does not support the commonly held belief that communication about end-of-life issues increases patient distress. However, conversations about care goals are often conducted by physicians who do not know the patient, do not routinely address patients' nonmedical goals, and often fail to provide patients with sufficient information about prognosis to allow appropriate decisions; in addition, they tend to occur so late in the patient's illness that their impact on care processes is reduced. This article (1) reviews the evidence and describes best practices in conversations about serious illness care goals and (2) offers practical advice for clinicians and health care systems about developing a systematic approach to quality and timing of such communication to assure that each patient has a personalized serious illness care plan. Best practices in discussing goals of care include the following: sharing prognostic information, eliciting decision-making preferences, understanding fears and goals, exploring views on trade-offs and impaired function, and wishes for family involvement. Several interventions hold promise in systematizing conversations with patients about serious illness care goals: better education of physicians; systems to identify and trigger early discussions for appropriate patients; patient and family education; structured formats to guide discussions; dedicated, structured sections in the electronic health record for recording information; and continuous measurement. We conclude that communication about serious illness care goals is an intervention that should be systematically integrated into our clinical care structures and processes.

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**E**ffective communication plays a major role in facilitating adaptation to illness realities, appropriate decision making, and quality of life<sup>1,2</sup> throughout the trajectory of a serious illness. As patients approach the end of life, communication about goals of care and planning is a key element in helping assure that patients receive the care they want, in alleviating anxiety, and in supporting families.<sup>3-5</sup> Effective communication supports, not only end-of-life care, but quality of life throughout the illness trajectory, even if death is not an imminent outcome.

In this review, we evaluate current practices in communication about serious illness, their effects on patients, and factors that may influence these practices; we conclude by identifying best practices in communication about goals of care in serious illness, primarily in the ambulatory setting. On the basis of this assessment, we propose a systematic approach, informed by evidence, to help assure that each seriously ill patient has a personalized serious illness treatment plan. The most common clinical conditions relevant to this discussion include cancer, congestive heart failure, chronic obstructive pulmonary disease, and chronic kidney disease and/or end-stage renal disease. This work was undertaken as part of the American College of Physicians (ACP) High Value

Care Initiative and subsequently endorsed by the High Value Task Force of the ACP.

### Methods

We conducted a narrative review of evidence about advance care planning and end-of-life communication practices to provide clinicians with practical, evidence-based advice. Both observational and intervention studies were included, as well as indirect evidence from high-quality studies of palliative care specialist interventions that address the impact of communication about serious illness care planning on outcomes. We use the term *serious illness care goals* to include discussions about goals of care, advance care planning, and end-of-life discussions for patients with serious illness to emphasize the targeted population and the potential impact on these discussions, not just for the very end of life but for care throughout the course of serious illness. In citing specific studies, we use the terms (eg, *end-of-life care*) used by the authors (see eMethods in the Supplement for a detailed description of methodology). For a summary of the ACP High Value Care Advice, see **Box 1**.

### Box 1. Summary of the American College of Physicians (ACP) High Value Care Advice on Communication in the Care of Patients With Serious and Life-Threatening Illness

#### Disease or Condition

Communication for patient with serious and life-threatening illness.

#### Target Audience

Internists (including oncologists, cardiologists, nephrologists, and intensivists), family physicians, and other clinicians who care for patients with serious and life-threatening illness.

#### Target Patient Population

All patients with serious and life-threatening illness.<sup>a</sup>

#### Indications for Communication

Examples:

Solid tumor with metastases, hypercalcemia, or spinal cord compression.

CHF, class III or IV with 2 or more hospitalizations.

CKD, on dialysis, age 75 years or older.

COPD, on home oxygen with FEV1 less than 35% predicted.

All patients whose physicians answer “no” to the following question: “Would you be surprised if this patient died in the next year?”

#### Evidence That Early Communication About Goals of Care and End-of-Life Preferences Improves Care

End-of-life conversations are associated with better quality of life, reduced use of life-sustaining treatments near death, earlier hospice referrals, and care that is more consistent with patient preferences.

Patients who received early palliative care showed significant improvements in quality of life and mood, and survived 25% longer.<sup>b</sup>

Patients who engaged in advance care planning were more likely to have their wishes known and followed.

Preparation for the end of life is associated with improved bereavement outcomes for family.

#### Potential Harms of Communication

Strong preponderance of evidence shows no increased depression, anxiety, hopelessness.

#### Potential Costs of Communication

Increased clinician time.

#### Harms of Failure to Address Goals of Care and/or End-of-Life Issues

Patient receipt of care not consistent with personal goals.

Worse quality of life.

Prolonged death with increased suffering.

Worse bereavement outcomes for family members.

Increased costs without benefit to patients.

#### Barriers to Communication

Patient factors: anxiety, denial, desire to protect family members.

Clinician factors: lack of training, comfort, and time, difficulties in prognostication.

System factors: life-sustaining care is the default, no systems for end-of-life care, poor systems for recording patient wishes, ambiguity about who is responsible.

#### Approaches to Overcome Barriers to Communication About Patient Values and Goals

Provide communication training for clinicians, especially about prognostication.

Improve documentation and exchange of information about patient values and goals through information technology.

Create real-time monitoring and feedback on performance for clinicians.

#### ACP High Value Care Advice

Communication about goals of care is a low-risk, high-value intervention for patients with serious and life-threatening illness; these discussions should begin early in the course of life-limiting illnesses. Ideally, communication about serious illness care goals should come from the patient's primary clinician even when a team of clinicians is involved with the patient's care. Early discussions about end-of-life care issues are associated with improved patient outcomes, including better quality of life, reduced use of nonbeneficial medical care near death, and care more consistent with patients' goals. This approach is also associated with improved family outcomes and reduced costs. Key elements of a system to help assure that every patient has a personalized serious illness care plan include training clinicians, identifying patients at risk of dying, preparing and educating patients, “triggering” physicians to conduct discussions at the appropriate time, having a structured communication format for goals of care discussions, establishing a system to assure documentation of these discussions, and using metrics to measure performance. The ACP supports the need for improving our approach to serious illness and end-of-life care, as well as the system changes needed to assure thoughtful and timely communication with patients and their family members across all health care settings.

<sup>a</sup> Serious illness (life expectancy <1 year).

<sup>b</sup> Evidence shows that palliative care consultation is approximately 50% communication and patient education.

Abbreviations: CHF, congestive heart failure; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease; FEV1, forced expiratory volume in the first second.

## Current Serious Illness Communication Practices

A consistent and large body of mostly observational research shows that patient, physician, and system factors all contribute to deficiencies in serious illness care communication.<sup>6,7</sup>

### Patient Factors

#### Patient Emotions

Patient emotions may inhibit discussion and understanding. Anxiety and denial are 2 critical patient-related factors that regularly

contribute to challenges in discussing serious illness care goals. All patients with a serious illness experience some anxiety; one-quarter to one-half of all patients with advanced cancer experience significant anxiety symptoms, and 2% to 14% have anxiety disorders.<sup>8</sup> Clinicians describe titrating discussions of end-of-life issues with patients to avoid overwhelming patients with anxiety. Avoidance may, in turn, make it more difficult for distressed patients to accept the realities of their illness and to engage in realistic planning for the future.

Denial of terminal illness is common and can be “healthy” if it facilitates adaptation. However, when denial impairs patients'

ability to appreciate reality and engage in an informed manner with key decisions, it becomes maladaptive. Denial tends to be amplified in situations of high anxiety and crisis, such as hospitalization; in such situations, patients often lack cognitive and emotional resources to manage strong feelings and difficult decisions, such as those related to end-of-life care.<sup>2</sup> Although guidelines recommend that initial discussions of goals of care and end-of-life preferences are best conducted when the patient is relatively stable,<sup>9</sup> the majority (55%) of first discussions in a large cancer population took place in the inpatient setting.<sup>2</sup>

In a recent study of patients with either metastatic lung or colorectal cancer, most (69% of those with lung cancer and 81% of those with colon cancer) did not understand that chemotherapy was very unlikely to cure their cancer.<sup>10</sup> The contribution of misunderstanding driven by patient emotions, as opposed to inadequate disclosure, is not known. One of the ramifications of this finding, however, is that anxiety, denial, and misunderstanding may make it difficult for patients to consider end-of-life care options such as hospice, even when such an option may be well-aligned with the patient's priorities.<sup>11</sup>

#### Patient Expectations

Patients, in general, expect their physicians to initiate discussions about advance care planning and end-of-life preferences.<sup>12</sup> In this context, physician reluctance to broach these issues may prevent them from occurring at all, leaving physicians to make decisions about care without adequate information about patients' wishes.

#### Differences in Patient Preferences

There is dramatic geographic variation in the use of intensive care services across the United States, leading to considerable variation in costs. Questions have been raised about whether intensive care that is provided in high-use geographic areas is beneficial.<sup>13,14</sup> Data suggest that differences in patient preferences are unlikely to explain regional variations in use of aggressive care at the end of life.<sup>15</sup>

#### Physician Factors

Physician attitudes appear to have considerable impact on whether and when these discussions occur, with physicians describing reluctance to initiate them when the patient appears well, does not have symptoms, or has not exhausted all treatment options.<sup>16</sup> Time constraints are cited by many physicians as a significant barrier<sup>17</sup> to end-of-life discussions.

#### End-of-Life Communication Training

Many physicians feel poorly prepared to conduct end-of-life conversations.<sup>18</sup> Although oncologists, nephrologists, and other clinicians need to communicate about end-of-life care with patients frequently (an average of 35 times a month for oncologists)<sup>19</sup> and express a strong desire for more learning about end-of-life communication, few trainees report receiving adequate training in communication about end-of-life issues.<sup>20</sup> For example, 72% of nephrology fellows report lack of preparation to manage the end-of-life care of a patient who stops dialysis and 73% were not taught how to communicate that a patient was dying.<sup>21</sup>

#### Comfort Level in Discussing End-of-Life Issues

Talking about death and dying can be distressing to patients and physicians alike. Physician barriers appear to be more common than pa-

tient barriers to end-of-life communication.<sup>16</sup> Physicians report that they are reluctant to initiate end-of-life discussions and are uncomfortable with the process because these discussions stir up difficult emotions.<sup>22</sup> Many physicians feel inadequate in managing the emotional and behavioral reactions of patients.<sup>23</sup>

#### Timing of Discussions

Physicians do not routinely initiate end-of-life discussions until late in the course of illness. In a large, population-based prospective cohort study of patients with metastatic lung and colorectal cancer, the first conversation about end-of-life care took place an average of 33 days before death.<sup>24</sup> Similarly, a large study of patients receiving dialysis found that 90% reported that their physicians had not discussed prognosis with them,<sup>7</sup> despite an annual mortality rate of 22%.

One effect of delay in discussions about end-of-life goals is that discussions of care options, such as hospice, which are associated with consistently superior outcomes for both patients and family members, occur very late in the patient's disease trajectory; 15% of hospice patients are referred in their last week of life, where benefits that accrue over time to the patient and family may be limited.<sup>25,26</sup> Earlier discussions about the realities of an advancing illness and the role of hospice care in meeting patient goals allows patients to choose the care trajectory that will best meet their goals.<sup>27</sup> Indeed, in a study of patients with gastrointestinal cancers examining potentially avoidable hospitalizations, rehospitalizations were 6 times less frequent in patients whose physician had discussed the option of hospice care.<sup>28</sup>

#### Uncertainty About Prognostic Accuracy

While a majority of patients want to discuss prognosis with physicians and the discussions are intimately linked to good personalized clinical decision making, many physicians hesitate to provide information because of uncertainty about prognostic accuracy and fear of harming the patient.<sup>29</sup> When they do discuss prognosis, physicians tend to be overly optimistic and to "shade" prognostic estimates in a favorable direction.<sup>30</sup> These practices influence patient decision making: patients with cancer who believed they were likely to live at least 6 months made decisions in favor of more interventions compared with patients who thought that there was at least a 10% chance of death within 6 months.<sup>31</sup> A subsequent study showed that these optimistic patients did, indeed, receive more life-sustaining treatments.<sup>32</sup>

#### Addressing Patients' and Families' Psychosocial Concerns

Physicians often do not address patients' and families' psychosocial concerns, including those about dying. Physicians tend to focus on diagnoses, treatments, and procedures in discussions about medical care at the end of life. While survival and treatment considerations are certainly significant to patients, the broad range of human concerns about the end of life—for loved ones, for spiritual well-being, for having the opportunity to say good bye, for independence and control, for comfort<sup>33</sup>—are often inadequately understood and integrated by physicians into the patient's overall treatment plan. Palliative care experts tend to explore these nonmedical issues and to be more patient centered in their discussions with patients about goals of care and end-of-life planning.

Patients regularly bring up concerns related to dying with their physicians to which the physicians do not respond.<sup>34</sup> In a study of

patients with congestive heart failure, 18% of patients expressed concerns about dying; physicians followed up on only 16% of these concerns.<sup>34</sup> Physicians frequently avoid these discussions by hedging (eg, not committing to a prognosis estimate when questioned) or changing the subject (eg, discussing diagnostic tests).<sup>34,35</sup>

### System Factors

#### Life-Sustaining Treatment as Default

Although over 70% of the Medicare population want interventions designed to palliate suffering at the end of their lives, even if it means living for less time,<sup>15</sup> our health care system is oriented toward providing life-sustaining treatment, unless a patient actively chooses against it. In the absence of conversations about prognosis, goals, and outcomes of treatment, patients do not have the opportunity to express their values and preferences, leading clinicians to assume that patients want additional interventions, even late in the illness. For example, among patients with chronic kidney disease receiving dialysis, 61% regretted initiating dialysis; 52% reported that dialysis was chosen because it was the physician's wish.<sup>7</sup>

Recent research suggests that more interventions and life-sustaining treatments are associated with poorer patient quality of life and higher levels of family distress.<sup>1,36</sup> Most patients wish to die at home and to avoid invasive measures,<sup>37,38</sup> yet most (52%) die in institutional settings, including hospitals and nursing homes,<sup>39</sup> and 29% die after a stay in the intensive care unit in the last 3 months of life.<sup>40-42</sup> In cancer care, palliative chemotherapy is used frequently in the last 3 months of life, with 12% of patients receiving chemotherapy within 14 days of death.<sup>40,43</sup> However, there appears to be no additional survival benefit in continuing treatment within 14 days of death.<sup>44</sup> While it is difficult to prospectively ascertain that a patient is within their last 2 weeks of life, and some patients will appropriately receive chemotherapy during this time, patients who receive chemotherapy in the last 2 weeks are less likely (51% vs 81%) to enroll in hospice or enroll late.<sup>44</sup> Receipt of palliative chemotherapy in the last 4 months of life was associated with an increased risk of undergoing cardiopulmonary resuscitation, mechanical ventilation, or both and of dying in an intensive care unit<sup>36</sup>; thus, chemotherapy in the last 14 days of life has been proposed as an indicator of poor-quality care.<sup>43</sup>

While numerous commonly used treatment approaches are appropriate for patients for whom the goal is life prolongation (eg, minimization of opioid use, hospitalization, intensive care unit admission), many of these treatments are inappropriate and ineffective for patients with very advanced disease. Conversely, patients who are approaching the end of life want and benefit from intensive psychosocial and spiritual support, careful but intensive use of medication for pain and other symptoms, and care in the home.<sup>33</sup> Because patients often are not aware that they are at the end of life, they may overuse life-prolonging treatment and underuse services that support quality of life (Box 2).

#### A Systematic Approach to Serious Illness Care Planning

Patients can plan for the end of life and make decisions about serious illness care goals through advance care planning—comprehensive, ongoing, patient-centered communication between physician and patient (or the patient's designated proxy) about values, treatment preferences, and goals of care.<sup>53</sup> The reported prevalence

### Box 2. Therapies With Potential Overuse and Underuse

#### Potential Overuse

Life-sustaining therapies at end of life<sup>13,15</sup>

Chemotherapy<sup>43</sup>

Radiation therapy<sup>45</sup>

Intensive care unit admission<sup>41</sup>

Surgery<sup>46</sup>

Feeding tubes<sup>47</sup>

Imaging<sup>48</sup>

Hospitalization<sup>39,42</sup>

Nonbeneficial medications<sup>49,50</sup>

#### Potential Underuse

Early conversations about serious illness care goals and values<sup>2</sup>

Hospice with length of stay greater than 14 days<sup>26</sup>

Family support<sup>39</sup>

Carefully titrated pain control with frequent follow-up<sup>51</sup>

Nonpain symptom management

Psychosocial and spiritual support<sup>52</sup>

in the United States of advance care planning varies between 18% and 70%.<sup>53-55</sup> Few health care systems have developed structures and processes that systematically address advance care planning, even for patients with serious illness; many physicians lack understanding of the process of advance care planning and how it affects care.<sup>56,57</sup>

#### Ambiguity About Who Is Responsible

Although early discussions about serious illness care *require* discussion in the ambulatory setting, discussions about goals of care are not routinely integrated into outpatient care. Indeed, the physician who is providing care for the patient's serious illness often does not conduct the goals of care conversation.

Patients report mixed views on their preferences about which clinician they prefer to engage with in discussing serious illness care planning.<sup>58,59</sup> Many primary care physicians report being unsure of their role in discussing preferences for future care when the patient is cared for by a specialist. Different specialists may have discussions of goals and treatment options, without adequate communication with other members of the team about what the patient's preferences are. Experts suggest that optimal care occurs when the multiple clinicians involved in the patient's care agree that 1 physician will assume primary responsibility for addressing and communicating about end-of-life issues and communicate the outcomes of these discussions to the entire team.<sup>60</sup>

#### Variation in Location and Quality of Documentation in EHRs

No consistent standard for location and quality of documentation in electronic health records (EHRs) exists. Electronic health records have become a major vehicle for communication about clinical care across a fragmented health system. However, information about serious illness care goals and advance care planning is not readily available or consistently recorded in the EHR for retrieval. Advance care planning information is found 69% of the time in prog-

**Box 3. Potential Triggers for End-of-Life Communication by Disease****Cancer<sup>81</sup>**

Prognosis-related triggers

"Would you be surprised if this patient died in the next year?"

Disease-based/condition-based criteria

All patients with non-small cell lung cancer, pancreatic cancer, glioblastoma

Patients older than 70 years with acute myelogenous leukemia

Treatment-based identification

Third-line chemotherapy

**Chronic Obstructive Pulmonary Disease<sup>6</sup>**

Lack of further treatment options

Functional decline

Symptom exacerbation

Ongoing oxygen requirement

Hospitalizations

**Congestive Heart Failure<sup>82</sup>**

Increased symptoms

Reduced function

Hospitalization

Progressive increase in diuretic need

Hypotension

Azotemia

Initiation of inotrope therapy

First or recurrent shock

**End-Stage Renal Disease<sup>83,84</sup>**

Prognosis-related triggers

"Would you be surprised if this patient died in the next year?"

Albumin level less than 3.5 g/dL

Age (as a continuous variable)

Dementia

Peripheral vascular disease

**General**Older than 80 years and hospitalized<sup>3</sup>Prognosis-based criteria (<http://www.epronosis.org>)<sup>85</sup>

ress notes, 43% in scanned documents, and 34% in problem lists, with many patients having documentation in multiple EHR locations, often with considerable inconsistencies.<sup>61</sup>

## Impact of Communication About Serious Illness Care Preferences

Although potentially time consuming,<sup>62</sup> absent, delayed, or inadequate communication about end-of-life preferences is associated with poor quality of life and anxiety, family distress,<sup>1,39</sup> prolongation of the dying process, undesired hospitalizations, patient mistrust of the health care system,<sup>32</sup> physician burnout,<sup>63</sup> and high costs.<sup>64-66</sup>

## Improved Clinical Outcomes

In a prospective, multisite study to assess coping of patients with cancer, investigators found that only 37% of a population of 332 patients, on average 4 months before death, reported having discussed end-of-life issues with their physicians.<sup>1</sup> When conversations were reported, patients reported better quality of life, received less aggressive medical care near death, and were referred earlier to hospice.<sup>1</sup> Patients who reported having had an end-of-life conversation were more likely to know that they were terminally ill, to report peacefulness, and to desire and receive less-invasive care.<sup>67</sup> Bereavement adjustment for families was also better.<sup>1</sup> However, patients who were less anxious about dying may have been more receptive to discussions about end-of-life care than those who were in more distress about their illness; further research is needed to clarify the directionality of this association. In a recent randomized clinical trial (RCT), patients with metastatic lung cancer were randomized at diagnosis to receive concurrent palliative and oncology care or oncology care alone (with palliative care consultation as needed).<sup>68</sup> Relative to the control population, palliative care patients had significantly better quality of life and mood, as well as 25% longer survival.<sup>68</sup> The primary focus of the palliative care intervention was on communication, patient education, and planning for care to address medical realities.<sup>69</sup>

Two recent studies of advance care planning in general medical populations also demonstrated positive results.<sup>3,70</sup> An RCT of an intervention designed to increase advance care planning discussions demonstrated that patients who received the intervention and died within 6 months were more likely to have their wishes known and followed (86% vs 30%).<sup>3</sup> A separate large study demonstrated that having a living will or health care agent was associated with a higher likelihood of patients receiving the care they desired at the end of life.<sup>70</sup> Further research is needed to confirm these findings.

## No Increase in Anxiety, Depression, and Loss of Hope

In general, the existing evidence does not support the commonly held belief that communication about goals of care and end-of-life issues increases patient anxiety, depression, and/or hopelessness.<sup>2,3,71,72</sup> Patients and families want open and honest information and a balance between realistic information and appropriate hope.<sup>73</sup> A study investigating surrogate decision makers' attitudes toward balancing hope and truth telling when discussing prognosis found that giving a sense of false hope or avoiding discussions about prognosis was viewed as an unacceptable way to maintain hope.<sup>74</sup> Surrogates believed that a realistic view of a patient's prognosis allowed them to better support the patient and each other.<sup>74</sup> However, if physicians are not trained to conduct sensitive, effective discussions, patients may be distressed by discussing these difficult issues.<sup>72</sup>

## Reduction in Surrogate Distress

Surrogates, usually family members, commonly are required to assume responsibility for medical decision making for patients and frequently experience negative sequelae from their role.<sup>75</sup> In a large study of patients older than 60 years, of those patients who required decisions, 70% did not have decision-making capacity, leaving decisions to surrogates or to previous advance directives.<sup>70</sup> In a systematic review, the effect of surrogate decision making had long-lasting negative consequences for a third of

**Box 4. A Systematic Approach to Discussions of Serious Illness Care Goals****Train Clinicians**

Interactive case-based sessions with communication skills practice are effective

- Participants show sustained improvement in patient-centered skills

- Significant improvement in responses to patients' emotional cues

Clinician training is necessary to enhance effectiveness of checklists, as in aviation and surgery<sup>86-88</sup>

**Identify Patients at Risk**

Standardize the timing and conduct of early goals of care discussions by identifying patients at high risk of death in the next year, for example:

- End-stage heart disease with two or more hospitalizations

- Poor-prognosis cancers

- Patients older than 75 years with end-stage renal disease

**"Trigger" Conversations in the Outpatient Setting Before a Crisis**

Develop criteria for appropriate timing of initial discussions (eg, all patients should have documentation of an initial conversation about serious illness care goals at the time of initiating second-line chemotherapy)

Make "triggers" a routine part of ambulatory care

**Educate Patients and Families**

Initiate discussions before decisions are required

Provide patients with appropriate information about prognosis, based on their information preferences and the limits of uncertainty

Focus initially on goals and values about care before discussing procedures

Encourage discussion of nonmedical goals

Encourage patients and their families to reflect on and clarify their wishes through discussion on an ongoing basis

**Use a Checklist or Conversation Guide**

Since conversations about serious illness care goals are challenging, high stress, and emotionally difficult for physicians and patients,<sup>78,91-93</sup> use of a checklist supports clinicians and assures completion of key steps in the conversations (see Figure)

**Improve Communication of Critical Information in the Electronic Medical Record**

Designate a site in the electronic medical record for a "single source of truth" for recording and retrieval of patients' values, goals, and preferences for care, as well as other key information, including:

- Health care proxy

- Medical orders for life-sustaining treatments

- Code status

**Measure and Report Performance**

Develop appropriate performance standards for high-quality care that include key indicators related to discussion and documentation of serious illness care goals

To accelerate improvement, simple measures of the presence of advance care planning information are likely to be inadequate.

Indicators of quality of discussion are essential

surrogates.<sup>75</sup> Common adverse effects cited by surrogates were stress, guilt over the decisions they made, and doubt regarding whether they had made the right decisions.<sup>75</sup> When surrogates knew which treatment was consistent with the patient's preferences, it reduced the negative effect of making decisions.

**Reduction in Costs**

Direct data on actual costs related to communication about advance care planning are limited, although there are several studies examining costs in palliative care.<sup>65,66,76</sup> In a multisite study investigating expenses and end-of-life discussions, costs were 35.7% lower among patients reporting having had an end-of-life discussion, with average cost savings of \$1041 per patient in the last week of life.<sup>64</sup> In a lung cancer palliative care RCT, those who received early and ongoing palliative care experienced fewer interventions and spent 29% less time in the hospital.<sup>68,69</sup> The ongoing communication about goals of care that is part of palliative care practice<sup>69</sup> may also have played a role in reducing hospitalizations. Increasing the practice of early end-of-life discussions has been proposed by experts as 1 of 5 key changes that can "bend the cost curve" for oncology care.<sup>77</sup>

**Data Summary**

Our review of the evidence demonstrates that there is consistent but often low- to moderate-quality evidence in the field of oncology for the benefits of discussions and emerging evidence in other

diseases (congestive heart failure, chronic obstructive lung disease, and chronic kidney disease). Data, especially from oncologic studies, show substantial and highly consistent associations between failure and delay in discussing end-of-life care options and poor outcomes. There is moderate-quality evidence from multiple studies that discussions do not harm oncology patients. We have not found any data about the impact of conducting early end-of-life discussions on subsequent clinician time investments (ie, an upfront investment of time could save time in the long run). A large, diverse, and consistent body of evidence demonstrates that early discussions of serious illness care goals are associated with beneficial outcomes for patients, without harmful adverse effects and with potential cost savings. Thus, we believe that there is a strong rationale for recommending that clinicians initiate early discussions with all patients with serious illness. However, more research, using high-quality methods, is needed to strengthen this conclusion and to better evaluate the impact of these discussions in nononcologic diseases.

**Practical Guidance for Clinicians**

A systematic, multicomponent intervention holds the greatest potential for improving serious illness care planning and is aligned with existing evidence. We propose the following steps: train clinicians<sup>78-80</sup> to enhance competencies in conducting discussions; identify patients at risk; develop "triggers" to assure discussions take place at the appropriate time (Box 3); use a checklist or

Figure. Serious Illness Conversation Guide

## Serious Illness Conversation Guide

<p><b>CLINICIAN STEPS</b></p> <p><input type="checkbox"/> <b>Set up</b></p> <ul style="list-style-type: none"> <li>• Thinking in advance</li> <li>• Is this okay?</li> <li>• Combined approach</li> <li>• Benefit for patient/family</li> <li>• No decisions today</li> </ul> <p><input type="checkbox"/> <b>Guide</b> (right column)</p> <p><input type="checkbox"/> <b>Summarize and confirm</b></p> <p><input type="checkbox"/> <b>Act</b></p> <ul style="list-style-type: none"> <li>• Affirm commitment</li> <li>• Make recommendations to patient</li> <li>• Document conversation</li> <li>• Provide patient with Family Communication Guide</li> </ul>	<p><b>CONVERSATION GUIDE</b></p> <p><b>Understanding</b>      What is your understanding now of where you are with your illness?</p> <hr/> <p><b>Information preferences</b>      How much information about what is likely to be ahead with your illness would you like from me?</p> <p style="font-size: small; margin-left: 20px;">FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.</p> <div style="background-color: #e0e0e0; padding: 5px; text-align: center; margin: 10px 0;"> <p><b>Prognosis</b>      <i>Share prognosis, tailored to information preferences</i></p> </div> <p><b>Goals</b>      If your health situation worsens, what are your most important goals?</p> <hr/> <p><b>Fears / Worries</b>      What are your biggest fears and worries about the future with your health?</p> <hr/> <p><b>Function</b>      What abilities are so critical to your life that you can't imagine living without them?</p> <hr/> <p><b>Trade-offs</b>      If you become sicker, how much are you willing to go through for the possibility of gaining more time?</p> <hr/> <p><b>Family</b>      How much does your family know about your priorities and wishes?</p> <p style="font-size: x-small; margin-left: 20px;">(Suggest bringing family and/or health care agent to next visit to discuss together)</p>
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conversation guide to support clinicians and assure adherence to best practices<sup>86-88</sup>; provide a structured documentation template for serious illness care goals in the EHR<sup>89</sup>; and measure performance<sup>90</sup> (Box 4). Key elements that should be addressed with patients are described in the Figure and include the following:

1. **Understanding of Prognosis:** Physicians should explore prognostic understanding to ascertain the patient's degree of awareness and acceptance of the diagnosis and illness course. This will allow the physician to titrate his or her discussion to address the patient's level of understanding<sup>78,91-94</sup> and respect patient vulnerabilities.
2. **Decision Making and Information Preferences:** Patient desire for information about the future can be a significant unmet need in serious illness.<sup>95</sup> Understanding the patient's preferences for information and for involvement in decision making allows the phy-

sician to provide desired information, helps the patient retain control, and gives the physician confidence in proceeding further into a difficult discussion.

3. **Prognostic Disclosure:** The physician has a responsibility to provide patients with information about prognosis to the degree desired by the patient (and within the limits knowable to the physician) to enable patients to factor this information into their decisions.<sup>96</sup> Information about what to expect about their illness, is considered "very important" by nearly all patients.<sup>29,33</sup>
4. **Patient Goals:** A focus on the broad array of goals that persons have for their health and well-being aids the physician in tailoring advice to address key patient life priorities and creating a personalized care plan. Furthermore, a focus on key goals allows the patient to retain a sense of purpose and control, which are antidotes to the hopelessness and despair that can arise in serious illness.

**Table. Communication Tips**

Do	Don't
Give a direct, honest prognosis <sup>99,101</sup>	Avoid responding to a patient request for information about prognosis <sup>102</sup>
Provide prognostic information as a range; acknowledge uncertainty, eg, "we think you have weeks to a small number of months, but it could be shorter or longer" <sup>103</sup>	Provide vague, eg, "incurable" or overly specific information, eg, "you have 6 months"
Allow silence <sup>104</sup>	Talk more than half the time <sup>104</sup>
Acknowledge and explore emotions <sup>105</sup>	Provide factual information in response to strong emotions
Focus on the patient's quality of life, goals, fears, and concerns <sup>33</sup>	Focus on medical procedures <sup>106</sup>

- Fears:** Fears about future suffering are a major component of patient distress.<sup>97</sup> Understanding the source and nature of these fears allows the patient to feel understood and supported and can allow the clinician to provide appropriate reassurance and to focus therapies to address patient concerns.
- Acceptable Function:** Patients view impairments in function differently and make different choices based on these perspectives. For some patients, maintenance of cognitive function is a *sine qua non* for existence to feel worthwhile; other patients may believe that not being able to eat or provide self-care are intolerable deficits that would make them ready to stop or reduce medical treatments. An opportunity to express views of critical abilities and tolerable and intolerable states helps guide these complex decisions.
- Trade-offs:** Patients may view time in the hospital, invasive procedures, or treatments differently, particularly when weighing these against the value of time at home or quality of life. Allowing patients to reflect on the trade-offs that might be necessary to achieve different outcomes promotes informed decision making.
- Family Involvement:** Patients vary in how involved they want family members to be and how much they want their own values, as

opposed to those of family members, to determine care at the end of life.<sup>98</sup> Family understanding of patient goals and preferences is associated with better outcomes for family members.<sup>74</sup> By exploring these issues with the patient, the clinician can help the patient develop a plan for engaging family members in these critical discussions.

## Basic Principles of End-of-Life Communication

- Patients want the truth about prognosis.<sup>99</sup>
- You will not harm your patient by talking about end-of-life issues.<sup>1</sup>
- Anxiety is normal for both patient and clinician during these discussions.<sup>100</sup>
- Patients have goals and priorities besides living longer.<sup>33</sup>
- Learning about patient goals and priorities empowers you to provide better care.
- For communication tips, see the **Table**.

## Conclusions

Although care of patients with serious illness has improved over the past 15 years, with the growth of hospice use and access to hospital and clinic-based palliative care services, many opportunities for improving serious illness care still exist. Nonpalliative care specialists will continue to be responsible for much of this care. Evidence is accumulating of the value of early discussions with patients about serious illness care goals as a key process for improving end-of-life outcomes. Conversations about serious illness care goals should be routinely integrated into clinical care processes by all physicians who care for this population of patients. Quality improvement principles teach us that identification of patients at high risk of death, clinician education, and instituting a systematic approach offer the best prospects of improving care.

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