Special Article

“I’d Recommend …” How to Incorporate Your Recommendation Into Shared Decision Making for Patients With Serious Illness

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Abstract

Patients and families facing serious illness often want and need their clinicians to help guide medical decision making by offering a recommendation. Yet clinicians worry that recommendations are not compatible with shared decision making and feel reluctant to offer them. We describe an expert approach to formulating a recommendation using a shared decision-making framework. We offer three steps to formulating a recommendation: 1) evaluate the prognosis and treatment options; 2) understand the range of priorities that are important to your patient given the prognosis; and 3) base your recommendation on the patient’s priorities most compatible with the likely prognosis and available treatment options.

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Introduction

Making a recommendation is an inherent part of all medical care—patients and families seek advice and guidance from medical practitioners as the experts in the treatment and management of disease and disability. However, medical practitioners usually approach decision making in the setting of a serious illness through a framework of shared decision making, a partnered process where clinicians and patients (or their surrogate decision maker) discuss how the available treatment options align with the patient’s goals and values, usually without a stated recommendation.1 In fact, one stated goal of shared decision making is “to replace the common decision making heuristic to ‘follow the doctor’s recommendation.””2

On first glance, a shared decision-making framework and a medical recommendation can seem incompatible; a recommendation can seem too directive for the partnered approach of shared decision making. In fact, many clinicians do not conceptualize making a recommendation as a component of shared decision making3 and do not routinely offer recommendations to patients and families.1,3 Clinicians worry that giving a recommendation may be too paternalistic and thus infringe on patient autonomy5 and bias decision making.6 Clinicians also are uncertain whether recommendations fit into a shared decision-making framework.7,8

However, when faced with serious illness decision making, compassionate guidance in the form of a recommendation is often welcomed by patients and families3,9,10 and is properly a part of shared decision making.8 Autonomy and shared decision making can only truly be promoted by making a recommendation because recommendations help patients make decisions that are more fully informed by medical expertise and awareness of the likely prognosis and outcomes6,11,12 and, in our experience, help patients and families to acknowledge and adapt to difficult medical realities. In contrast, asking neutral questions

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can provoke misunderstanding and may cause harm by biasing patients and families to choose treatments that clinicians believe offer little benefit. Guidance in the form of a recommendation is particularly important toward the end of life, when patients and families must make high-stakes medical decisions under challenging circumstances, often managing their own emotions and family dynamics, as well as the uncertainty of the prognosis and outcomes.

Within a shared decision-making framework, clinicians can give a recommendation based on the goals and values expressed by the patient: Patients and families are the experts in the patient’s values, goals, and preferences, whereas, medical professionals are the experts in the treatment options that honor the patient’s perspective. A recommendation helps translate values and goals into a treatment plan. Because a shared decision-making framework with a recommendation may be unfamiliar, we offer detailed guidance, giving three steps to formulate a recommendation. Then, we answer frequently asked questions about making a recommendation. The following case will illustrate the steps. The case concerns a particular disease, but these issues arise in many illness trajectories.

**The Case**

Dr. J worries increasingly about her patient Dave. Dave is 68, has advanced idiopathic pulmonary fibrosis, and is declining quickly despite all available treatments. Dave is also full code and wants to try all possible options. In discussions, Dave has prioritized fighting the disease so that he could spend time with family. However, Dr. J worries he is no longer likely to benefit from disease-directed hospital-based treatment and that cardiopulmonary resuscitation (CPR) will most likely prolong Dave’s dying and not significantly improve his quality or length of life or ability to spend time with family. She also worries that a focus on disease-modifying therapies may preclude important work that Dave could do around life closure and prevent him from using services such as hospice, which could help support him and his family.

Dr. J wants to recommend an approach focused on comfort but feels uncomfortable about doing so. On the one hand, she can see that Dave is declining quickly and needs guidance about his medical care. She suspects that it is hard for him to realize how sick he is and that it could be helpful for her to outline a plan of care. On the other hand, Dr. J feels uncertain about infringing on Dave’s autonomy when she can see he is struggling to accept the prognosis and trying to assert his wish for more time. She is not sure that it is her role to be directive about personal high-stakes decisions such as CPR or hospice.

**Step 1: Evaluate the Prognosis and Treatment Options**

To offer Dave a recommendation using a shared decision-making framework, Dr. J needs to translate his goals and values into a medical plan that is consistent with the prognosis and treatment options. Practically, it does not work to first learn the patient’s goals and values, as this leaves the clinician unprepared for the inevitable discussion about treatment options that follows. So, before speaking with Dave, Dr. J should first evaluate the prognosis and treatment options (Step 1).

Because prognostic information is often uncertain, speaking to specialists or other clinicians involved in the case can help to define a probable range or develop a consensus about what period or functional decline is most likely (NB: prognosis is as much about time as it is about projected functional decline, which patients also value understanding). Benefits and burdens of a given treatment are uniquely related to the specific illness and prognosis of the individual patient as well as psychosocial and spiritual factors. Especially in the age of personalized or precision medicine, the uniqueness of the patient and his and/or her disease should be considered. For example, parenteral fluids at the end of life are unlikely to improve delirium and symptoms of dehydration, especially in cancer patients. Although there may be some patients who benefit, often parenteral fluids worsen fluid overload states such as congestive heart or renal failure. So, whether IV fluids have the potential to be beneficial depends on the individual patient’s clinical condition. Because the clinician’s primary responsibility is to protect the patient from harm, clinicians should not offer treatments they do not think will be helpful to that patient.

Once the clinician has a sense of the prognosis and available treatments, she and/or he can further prepare for shared decision making by considering how these treatments might impact commonly held values such as quality of life, length of life, suffering, the ability to be at home or with family, and time spent in the hospital or other institutional settings. Forming an opinion about how treatments relate to commonly held values helps build a deeper synthesis of the medical information that incorporates the clinician’s experience and intuition (Table 1).

In particular, it can be helpful to prepare for two common situations. First, many patients want to live as well as possible for as long as possible. Prepare to talk about how to best do this. Second, many patients and families will ask their clinician his and/or her own opinion, “If this were your father, what would you do?” or “If you were in my position, what would you do?” Prepare to answer this question. In asking this type of question,
patients and families are looking for guidance. The clinician should be explicit about what values are in-
informed his and/or her own opinion so that patients and families can better understand the decision-
making process and transfer the relevant components of the process to their own situation. For example, “I
know that my father values being at home, even if that means he might live for a shorter time. So, if this were my father, I
would suggest ...”

Forming an opinion about how treatment options relate to commonly held values and considering the
decision for oneself is a reflective practice that enables the clinician to develop a deeper sense of their own
feelings about the medical decision at hand. Unrecog-
nized feelings and attitudes can interfere with how cli-
nicians connect with and support patients by hindering the clinician’s ability to convey empathy, 25
distorting meaningful discussion, and leading to underinvolvement or overinvolvement. 26–28 Whereas
self-awareness improves clinician’s abilities to be atten-
tive, listen deeply, and respond more effectively. 29

Figure 1 shows Dave’s treatment options at the time
when his clinician estimates his prognosis to be three
to six months. Some options, such as antibiotics for an
infection, are not needed at present but are repre-
sented because they have the potential to offer benefit
under specific circumstances. (Toward end of life,
consideration should be given to patient preference
for antibiotics, potential impact on symptom control,
and possible negative side effects. 30,31 ) The shaded
area of the circle contains options that the clinician
would be justified in not recommending because they are unlikely to offer benefit or cause substantial
harm for a slim chance of benefit, for example, CPR. 17 The options in the shaded area are determined
by Dave’s medical condition and may change over
time.

This first step of reflecting on the prognosis and
treatment options, although easily skipped, is essen-
tial to guiding patients effectively through serious
illness decision making. By reflecting on what treat-
ments may be helpful, the clinician can clarify for
the patient what is still possible. By reflecting on
what treatments no longer offer benefit, the clinician
is more prepared to recommend against some treat-
ments despite the medical uncertainty. Too often,
the unavoidable medical uncertainty—that it is
impossible to know the future—hinders clinicians
and prevents them from making a recommendation
although recommendations are wanted and valued
by patients. 3,9,10 In Steps 2 and 3 of the decision-
making process, described later, the clinician will
evaluate the treatments within the context of what
is important to the patient.

Table 1

<table>
<thead>
<tr>
<th>Step</th>
<th>What would I recommend to my own family? What values are my recommendations based on?</th>
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<tbody>
<tr>
<td>1</td>
<td>Estimate the prognosis: How much time does the patient likely have? How will the patient’s function change over time? What would one share if the patient asks for prognostic information? Consider the treatments: What treatments do I think could safely be offered to the patient that would have a reasonable likelihood of benefit? Form a values-based opinion: What is the burden of these possible treatments? What options best maximize quality of life? Length of life? What options minimize symptom burden? What would I recommend to my own family? What values are my recommendations based on?</td>
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for more than one answer to the question of what is most important. For example, “What else is important to you?” or “If your health continued to decline, what would be most important to you then?” By encouraging a range of hopes and goals, the clinician helps the patient allow for, and ultimately prepare for, many different outcomes. More frightening goals, such as a comfortable death, can be more easily articulated when they are discussed as one of many possibilities.32 With an in-depth discussion, Dave expressed a range of priorities (Fig. 1).

**Step 3: Base the Recommendation on the Patients’ Priorities Most Compatible With the Likely Prognosis and Available Treatment Options**

To formulate a recommendation, the clinician integrates his or her understanding of the prognosis and treatment options (Step 1) with what is important to the patient (Step 2). From an ethical perspective, this step more likely honors patient autonomy and prevents the clinician from abrogating the responsibility to provide guidance.18 This third step involves clinical judgment as the clinician must choose which of the patient’s goals and values to focus on, based on what is possible given the prognosis and available treatment options (Fig. 1). The following frequently asked questions illustrate the process.

**How do I Formulate a Recommendation When the Patient Has Many Different Priorities?**

In Dave’s case, he had several priorities, including staying positive, fighting the illness, spending time with family, doing everything that might help, and dying peacefully at the end. Because the clinician estimated the prognosis as three to six months and thought hospital-based treatments would not offer significant benefit, she based her recommendation on the priorities most consistent with this assessment, which were spending time with family, doing everything that might help, and dying peacefully at the end. The recommendation was for a tailored medical plan to avoid hospitalization and treat potentially reversible conditions when needed in the home setting by using modalities, such as bilevel positive airway pressure (BiPAP), antibiotics, anticoagulation, IV fluids, and oxygen. Hospice was recommended as the best program to support this medical plan.

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**Fig. 1.** Three steps to formulating a recommendation. BiPAP = bilevel positive airway pressure; CPR = cardiopulmonary resuscitation; ICU = intensive care unit; MOLST = Medical Orders for Life-Sustaining Treatment.
Should I Explicitly Discuss and Recommend Against All the Treatments That I Think Are Nonbeneficial?

The clinician does not need to discuss every possible nonbeneficial treatment with the patient. Because these treatments do not offer the possibility for benefit, they are often not relevant to the patient’s and family/surrogate’s decision-making process. When Dave enrolled in hospice, the clinician did not think that CPR, enteral/parenteral nutrition, or intensive care would be beneficial for Dave. She did not explicitly recommend against enteral/parenteral nutrition or intensive care but rather recommended a medical plan to meet Dave’s goals. However, the clinician did specifically recommend against CPR and other life-sustaining treatments. Because the default option in our medical culture is for CPR, the clinician needed to specifically recommend against CPR, so that Dave could assent to forgoing this option and document this choice.13

How Do I Offer or Introduce a Recommendation?

After discussing the patient’s unique goals and values and the treatment options, the clinician can then ask patients or surrogates their preference about a recommendation, “Would it be helpful if I offered a recommendation?”38 When patients seem stuck or overwhelmed by the medical options, the clinician can also directly offer a recommendation that incorporates patient values, “Given what you have told me about what is important to you, I would recommend …”9

For example, at a follow-up visit after enrolling in hospice, Dave’s partner asked the clinician what should happen if Dave suddenly decompensated in a coughing fit and lost consciousness. Dave’s partner was unsure if he should call 911 for help or allow Dave to die. In response, the clinician drew on what she knew was important to Dave and her understanding of the prognosis. “It sounds like what is most important right now is being with family and having a peaceful death.” Both Dave and his partner agreed. The clinician continued, “Given these goals, I recommend that if Dave has a coughing fit and becomes unconscious, that we have a plan to keep him comfortable and allow him to die naturally at home.”

What if the Patient/Family/Surrogate Does Not Accept the Recommendation?

In acute or clinically unstable situations, the clinician may need to outline a plan of care although the patient and family are emotionally overwhelmed or exhausted. Naming the feelings in the room, “I can see that this is difficult and sad,” can invite reflection and offer a needed pause. Being able to make a medical recommendation when patients and families are feeling overwhelmed gives physicians flexibility to guide difficult decision making by bearing some of the responsibility for those decisions.6 “Given what is happening at this time, and how overwhelming all of this is, I wonder if it would be helpful for me to offer a recommendation …”

What Happens if the Patient/Family/Surrogate Does Not Accept the Recommendation?

Patients always have the option to decline the recommendation.39 Some patients want more time to think things over or to discuss with family members. In such situations, the clinician continues to support and guide the patient and family through the illness. Statements of nonabandonment such as, “We will continue to figure this out together,”40 can help reinforce to the patient that the clinician continues to be actively involved and supportive, although the recommendation for care has not been accepted.

Other patients or families may voice hesitation to accept the recommendation. For example, “I just want to focus on being positive” or “It’s her decision to make and she wants to keep fighting.” When faced with hesitation, it can be helpful for the clinician to acknowledge the underlying values expressed by the patient or family. “I can hear that it is important for you to stay positive and hope for good things” or “Your mother has been so strong through this illness.” Once these values are acknowledged, the clinician can decide if further discussion is warranted depending on the clinical urgency.

In nonurgent situations, the clinician may defer further conversation, “I know that it is important to stay positive and I am worried that we are going to need to keep thinking about this. Let’s check in and talk more on our next visit.” By expressing worry and forecasting the need for further discussion, the clinician prepares the patient or family for future conversations. In more clinically urgent situations, the clinician may invite further discussion, “On the one hand, I know that this is difficult to talk about and that it is important to stay positive. On the other hand, I worry that things are changing medically, and that we need to be prepared. Can we talk more about what if things don’t go as we hope?” By naming the dilemma of wanting to stay positive and needing to be prepared,32 the clinician addresses ambivalence and offers a path forward that acknowledges the importance of hope and allows for further discussion.
What if I Feel Uncomfortable Making a Recommendation?

We feel uncomfortable making recommendations because we are not sure how to provide needed medical guidance to patients and families while still respecting patient autonomy. In one study, nearly all residents felt CPR would be unhelpful, yet a majority (69%) were unwilling to offer this recommendation stating that deference to patient autonomy prevented them from providing guidance.5

In our experience, the process of making a recommendation can be made easier by recognizing that many patients and surrogate decision makers want their physicians to take some of the responsibility for medical decision making by making a recommendation3,9,10,38,41 and that respect for patient autonomy or the desire to engage in shared decision making need not be seen as barriers in this process. In fact, simply asking patients about their preferences for various interventions, for example, their desire for CPR or not, does not necessarily respect patient autonomy and may even compromise patient autonomy in preventing the patient from making a fully informed decision, guided by their own values.18

Making a recommendation is a communication skill that can be learned with practice.4,42 If you feel uncomfortable making recommendations, we suggest learning how via a graded approach. Thus, practice in clinical situations that lend themselves easier to a recommendation. Here are examples:

- The patient asks for a recommendation.
- You have a close relationship with the patient and sense that she and/or he trusts you.
- There are limited options, and you feel strongly that there is a best course of action.
- The decision is relatively low stakes. For example, you might recommend that the patients talk with their health care agent about their goals and values. “I recommend that you sit down and talk with your son about what is most important to you if you were to get sicker.”

Conclusion

Many patients and families want their clinicians to help guide them through medical decision making. We have presented a three-step process using a shared decision-making framework for formulating a recommendation that integrates a patient-specific evaluation of the prognosis and treatment options with what is most important to the patient. In our experience, as clinicians practice making recommendations, we become more skilled and more comfortable guiding complex medical decision making to the benefit of our patients and families.

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