Remembering the Patient in Discussions About Serious Illness: Moving From Decisions to Recommendations

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Making decisions. It's what we do. Every day. Every patient. We diagnose, construct treatment plans, change the course, or decide to hold tight. Sometimes we involve colleagues when we need help—a surgeon, a radiologist, a physical therapist—especially when the illness is complicated. With this input, we decide what is best. Usually, it all works out. Successes reinforce the approach, and we repeat it.

While in the *real* world of clinical medicine, this approach happens commonly,[1–3] it is missing a crucial element: the patient.[4] Take Dan, a 67-year-old man with end-stage cirrhosis who had been in the hospital and rehabilitation for 6 months before this admission. Slowly, and then all at once, Dan was dying. Clearly, it was not enough simply to tell Dan our decision—it was time for hospice. "Making decisions" may have worked well enough for titrating his diuretics or choosing antibiotics for his infected ascites, but now was different.

A few years ago, our hospital began a health system–wide initiative to help non–palliative care faculty, residents, and other clinicians enhance their communication skills with patients and families facing serious illnesses. The initiative was based on an approach called the Serious Illness Care Program, which incorporates a guide to assist with discussions (provided as online supplemental material).[5] While learning to use the guide initially seemed awkward, the benefits of the structured content rapidly became apparent to many learners, even to some seasoned skeptics, because it efficiently helped them understand 2 crucial dimensions of patients—their prognostic awareness and their priorities regarding their health—both of which are fundamental to constructing an appropriate care plan *with* patients rather than *for* patients.

The first dimension, prognostic awareness, ensures patients have a reasonable level of understanding of the likely future of their illnesses. It also helps clinicians recognize that patients cope with serious illness by experiencing times when they are more worried about the future (and seem to understand their prognosis) and times when they are even quite hopeful, such that it can sometimes seem as if they have never been told prognostic information.[6] Having contradictory hopes and worries is healthy, normal, and adaptive, and not necessarily a sign that patients are in denial or not ready to talk about the bigger picture. The guide approaches prognostic awareness through 3 questions: "What is your understanding of your illness?" "Looking to the future, what are your hopes?" "What are your worries?"

With a better understanding of the patient's prognostic awareness, residents and faculty can explore the next dimension—the patient's priorities. Delineating priorities facilitates shared decision making by enabling clinicians to make medical recommendations that align with what matters most to the patient. Priorities may evolve over time, highlighting the need for these conversations to happen iteratively. Even if some priorities become less possible due to illness progression, it is important for clinicians to be aware of them. Asking "If your health does worsen, what is most important to you?" helps to begin the exploration.

For Dan, we learned that what was most important was having as much time as possible to spend with family and dying peacefully, at home. Knowing that Dan had exhausted his therapeutic options, together we developed a plan that honored these priorities to the extent that they were medically possible: no further paracenteses to maximize his time at home and entering hospice.

But why use a script?

There are many reasons. First, the script improves the quality of conversations by ensuring we routinely ask about patients' prognostic awareness and priorities. Second, the script helps residents and attending physicians stay on track and progress through these conversations, which can be difficult as they may provoke anxiety for both patients and clinicians.

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Editor's Note: The online version of this article contains the Serious Illness Care Program guide.

Third, physicians have cited a lack of time as a barrier to talking with patients about their illness[7]; the script has been shown to help physicians move through complex discussions expeditiously.[8] The scripted structure can also make documentation in the electronic health record efficient.

Finally, the script serves as a simple and concrete teaching tool. Residents and attending physicians report a wide variety of formal training with communication techniques.[6,9] Rather than requiring them to determine their own effective approach via trial and error (with the potential for poor outcomes[10]), a scripted approach offers learners a structure to build competency efficiently.[11] Clinicians trained to use the guide find the approach acceptable and report a significant improvement in communication skills.[12] Furthermore, the guide is an open source document licensed through Creative Commons and is therefore freely available and modifiable.

As we work to improve our own skills—and those of our trainees—in taking care of patients facing serious illness, there is commonly more than one medical option to consider. Continue treatment or stop it. Try something new or press on with the current plan. Focus on disease management or focus on symptom control. It is rare that a thoughtful clinician sees only one path. Understanding the patient's prognostic awareness and priorities puts a thumb on the scale of these options, tipping it in the direction that best balances clinical reasoning with a deeper understanding of the patient.

Making decisions. It's what we do. And sometimes, that's okay. When we need a decision that is based solely on clinical expertise (eg, which radiograph to choose or which blood test is most appropriate), we are trained to decide and move on. But often, especially when a patient is facing a serious illness or other important decisions are needed, we should be more deliberate—and help our trainees to perform similarly—about incorporating the patient into our approach, reframing it from making a decision to making the most appropriate patient-centered recommendation.

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