

# Virtual Mentor

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## STATE OF THE ART AND SCIENCE

### Serious Illness Communications Checklist

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End-of-life care in America has changed dramatically over the last 40 years. Prior to the 1970s, there were no do-not-resuscitate (DNR) orders, hospices, or palliative care units, little research or physician education on how best to care for patients at the end of life, and little attention on the decisions surrounding end-of-life care. Since then, concerted educational, political, social, cultural, and legal efforts have led to significant changes in the way doctors, patients, families, and society think about and respond to advanced illness.

The remarkable advances in medicine in the last half century have also created many new challenges in thinking about and planning for end-of-life care. Median life expectancy in the U.S. has increased from 46 years in 1900 to 78.7 years a century later [1]. In the past, death often just happened. Now, an increasing number of people are living longer, often with chronic illness, and facing choices about how, when, and where they prefer death to occur. The proliferation of high-tech, life-sustaining interventions and a culture of “never say die” have forced patients and families to confront difficult end-of-life choices. We do not have an adequate process to systematically support patients and their families in considering the choices they might confront.

Numerous studies show that patients want to have conversations about end-of-life care and expect their physicians to initiate these discussions [2-4]. The goal of conversations between patients and clinicians about end-of-life care is to help patients to live as well as possible, adjust to the realities of their illnesses, consider alternative treatment priorities, and plan and prepare for the end of life. And much evidence suggests that, when these conversations occur, there is greater concordance between patients’ wishes and the care they receive [5]; better patient quality of life [6]; less use of nonbeneficial life-sustaining treatment [7]; more use of hospice care (which allows patients to remain at home) [7]; reduced family distress [7]; and reduced overall resource use [8].

Physicians, however, do not feel comfortable having these conversations and, in fact, identify more barriers to having these discussions than patients do [9]. Physicians are often uncomfortable with the strong emotions that are often stirred up by discussions about end-of-life issues. Yet addressing emotions directly is consistent with best practices by palliative care experts and is associated with improved outcomes [7].

The many therapeutic options now available to patients with advanced disease may lead physicians to focus on the details of intervention options, rather than the patient's goals, such as being at home, minimizing suffering, or not burdening family members. Many clinicians are unprepared and untrained to conduct high-quality end-of-life conversations [10] and may avoid them as a consequence [11].

Palliative care experts routinely use emotion-focused conversations to elicit values and goals. Many physicians fear that these conversations will take too long—and they do take time. However, this process allows patient, physician, and often family to come to understandings that create a personalized end-of-life care plan that is aligned with patient wishes and goals.

Another practice supported by palliative care specialists is the concept of “just in time” decision making [12]. Rather than making *final* decisions regarding future care and interventions, the goal is to encourage earlier end-of-life communication that aims to *prepare* the patient, his or her family members, and clinicians to make better decisions when challenges arise in the future. In this way, “just in time” decision making avoids some of the pitfalls of advance care planning [13] such as premature decision making without enough information.

While palliative care physicians are an excellent resource for end-of-life conversations, there is already a shortage of approximately 11,000 palliative medicine physicians for hospices and hospital-based palliative care programs [14]. Thus, it is not possible for all patients to be seen by palliative care physicians to discuss end-of-life issues. Hence, all physicians who care for seriously ill patients must become competent in conducting these discussions.

In addition, physicians need training in evaluating and communicating about prognostic information, including the challenges in dealing with uncertainty. Assessing the patient's understanding of prognosis and desires for information about the future allows the clinician to provide prognostic information in a patient-centered manner, and patients choose less aggressive treatments when they understand that their life expectancy may be short [15].

Advance care planning should encourage patients to express individual preferences and concerns in an open-ended manner. At the same time, certain key information should be ascertained and communicated to all clinicians in an electronic format, especially given the multiple care transitions that are likely to occur. Crucial aspects of patient information regarding values and goals are often not readily accessible in the electronic medical record.

To address these needs, we developed a structured communication format called the Serious Illness Communication Checklist for physicians to use at the point when they “would not be surprised” if the patient died within the coming year [16, 17]. Clinicians are asked to review their patient panels, ask the “surprise question,” and then conduct a “checklist conversation” with appropriate patients. Checklists are

tools developed to ensure adherence to key processes and are commonly used in high-stress, high-risk fields such as aviation and nuclear power. They ensure completion of necessary tasks during complex, stressful situations in which memory alone may not be sufficient, or when stress and discomfort felt by those participating in the scenarios may cloud clear thought processes, interfere with effective communication, and prevent accomplishment of desired outcomes.

The goal of the Serious Illness Communication Checklist is to improve care for patients with serious illnesses and their families by providing clinicians with a tool to facilitate discussions about end-of-life issues at the right time in the right way and to document the vital information that the discussion elicits. This discussion is patient-centered and assesses their understanding of prognosis, their information preferences, personal goals, fears and worries, willingness to tolerate suffering, and quality of life considerations. These are relatively standard topics of goals-of-care discussions; the structure of the checklist provides a systematic approach to developing a personalized end-of-life treatment plan for each patient.

Conversations between patients, families and clinicians about values and goals will enhance patient understanding and control of their own medical decisions, ease the burdens of decision-making on family members, and help patients toward achieving peace as they approach the end of life. This systematic approach to patient-centered communication based on best practices and existing evidence could transform the way end-of-life care is delivered.

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