

# Dana-Farber Program Seeks to Improve Conversations with Patients with Serious Illness

BY LOLA BUTCHER

Last summer, 180 physicians, nurses, social workers and other health care professionals from around the country gathered at Harvard Medical School for two and a half days to learn about the Serious Illness Care Program, an initiative to improve the care of patients facing a life-threatening illness.

“They were there to not only transform their own practice, but also improve care for patients with serious illness at their own clinics and systems,” explained Joanna Paladino, MD, Assistant Director of Serious Illness Care implementation at Ariadne Labs and Instructor of Medicine in Palliative Care at Dana-Farber Cancer Institute.

The continuing medical education course, which will be offered again in June, is one of several ways that Paladino and her colleagues are disseminating the program’s protocols and tools across the country.

The program’s overarching goals are to enable patients with cancer and other serious illnesses to live the best life possible and to ensure they get the kind of care that they want. The basic strategy is to foster meaningful conversations between those patients, their clinicians, and their family members so that patients’ wishes are understood and honored.

“Research shows that earlier conversations about patients’ values and goals are associated with better outcomes, such as improved quality of life for patients and better patient and family coping,” Paladino said. “But the truth is, these discussions are difficult.”

## How It Started

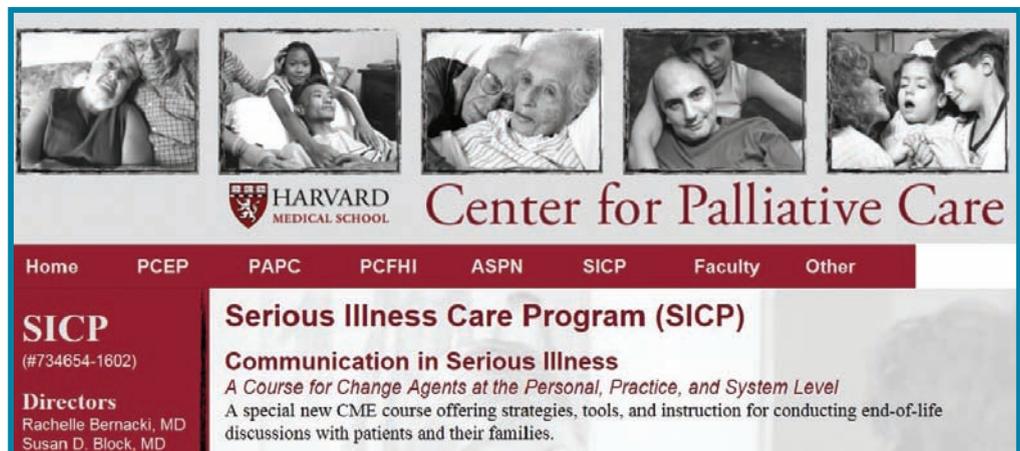
Serious Illness Care is one of several programs at Ariadne Labs, a center for health systems innovation directed by Atul Gawande, MD, a surgeon at Brigham and Women’s Hospital and professor at the Harvard T.H. Chan School of Public Health. A writer and health policy researcher, Gawande is the author of four books, including *Being Mortal: Medicine and What Matters in the End* (OT 12/25/14 issue). Ariadne is a joint center of Brigham and Women’s and the Harvard T. H Chan School of Public Health.

Unsatisfied with the discussions he had with his own seriously ill patients who were facing surgery, Gawande sought to learn from clinical experts in palliative care. That led him to

Susan Block, MD, founding Chair of the Department of Psychosocial Oncology and Palliative Care at Dana-Farber and Brigham and Women’s and co-founder of the Harvard Medical

creators envision. The program involves several components:

- Identifying patients with serious illness who would benefit from these conversations;



School Center for Palliative Care. She shared her list of open-ended questions for Gawande to experiment with on his own.

“He came back to Susan a few weeks later and said that it completely transformed his practice,” Paladino said. “He felt connected to his patients in a way that he hadn’t before, and he felt that he was able to guide patients through a process

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of articulating their goals, making informed decisions and getting the care that they wanted.”

The Serious Illness Care Program was created to extend those questions—and the training needed to use them effectively—to all clinicians.

## Progress to Date

Today, Block is director of the program and, along with Paladino and Rachelle Bernacki, MD, is leading a four-year randomized controlled trial at Dana-Farber to see if the program works as its

• Training clinicians and health professionals to have patient-centered conversations about their values and goals;

• Reminding clinicians to start the discussions at the appropriate time;

• Engaging in conversations with patients using the Serious Illness Conversation Guide;

• Creating a “single source of truth” so that clinicians document the conversations—and the patients’ personal goals—in a single place that all clinicians can see; and

• Providing materials to patients and families to encourage continued conversations at home.

The trial is now in its third year. More than 70 percent of Dana-Farber’s oncologists, physician assistants, and nurse practitioners enrolled, suggesting they were eager to improve the quality of conversations they have with patients, Paladino said. All but one of the clinicians assigned to the intervention group completed the training, and 97 percent of those have used the conversation guide in their practice.

Although the trial is still ongoing, the program is being disseminated broadly. In addition to the Harvard continuing medical education program for clinicians, Ariadne is partnering with major health systems across the country to introduce the conversation guide and program protocols at the institutional level.

Ariadne researchers shared early findings at the Palliative Care in Oncology Symposium in October:

• The Serious Illness Care training program is widely adopted and viewed as effective by clinicians (average rating 4.3 out of 5);

• The intervention results in significantly more patients who have a goals-of-care conversation before death

## SERIOUS ILLNESS CARE PROGRAM

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(92 percent intervention vs. 70 percent control);

- 86 percent of patients who had the Serious Illness Conversation with their oncology clinician said they found it worthwhile;

- The conversations are occurring on average three months earlier in the intervention group; and

- The intervention significantly lowers patient anxiety and depression for patients with moderate to severe symptoms.

“It is supporting oncology clinicians in having more, earlier, and better conversations with their patients with advanced cancer about their values and goals,” Paladino said. “We’re also learning from our preliminary results that the conversations help reduce patient anxiety and depression, and that patients are reporting positive impact on their lives.”

Preliminary results also show where improvement is needed. The program is using the “surprise question” to identify patients who will be recruited to participate in the trial (*OT*, 11/25/15). Oncology clinicians are asked to review lists of patients they have seen at least four times—so that they are well acquainted with each patient—and have seen in recent weeks. They are asked to answer the question “Would you be surprised if this patient died within a year?” for each patient on the list.

Research presented at the symposium showed that patients identified as being at high risk of dying within the next year were, in fact, more likely to do so than patients who were not identified. However, the surprise question missed 40 percent of patients who did die within the year.

“It is an imperfect screening tool because our goal is to make sure that all people with serious illness have the opportunity to have these conversations,” Paladino said. “There’s a lot more work to be done on how we can best identify patients. We need to learn how the patients who were identified were different from those who weren’t so we

can understand how to improve our process.”

### Still More to Learn

In addition to the trial at Dana-Farber, the Serious Illness Care Program is being evaluated in several other research projects:

- **Primary care:** Ariadne Labs and Partners HealthCare have trained primary care team members at several clinics in the Boston area on the use of the conversation guide. The research team is evaluating whether the program can be effectively implemented with complex, high-risk primary care patients.

- **Dialysis centers:** The five-year survival rate for patients with chronic kidney disease on dialysis is 20 percent, but communication about patients’ values and care preferences is not standard practice in nephrology. Dialysis clinicians and patients at Brigham and Women’s Faulkner Hospital are being enrolled in a trial to explore implementation of the program in a dialysis unit.

- **Long-term acute care:** The conversation guide was modified and evaluated for use with patients with chronic critical illness who were hospitalized in a long-term acute-care hospital.

- **Cross-cultural adaptation:** Ariadne researchers are working in South Carolina to understand the acceptability of the conversation guide in African American communities, with the goal of recommending modifications that will make it more generalizable in diverse settings.

- **Emergency setting:** A team is working to develop a script that surgeons can use with patients who have advanced disease and need surgery for a sudden, life-threatening problem.

### How the Conversation Guide Works

The goal of the Serious Illness Conversation Guide is to go beyond the standard discussion about procedures and treatments (*see box*).

“Patients living with advanced cancer—or any serious illness—have

priorities besides just living longer, such as spending time with their loved ones and achieving personal goals,” Paladino said. “One of our approaches is to change the conversation so that patients can share their goals, their hopes, their fears, and what is most important to them, which can provide a really strong foundation for making patient-centered decisions about their medical care when they are in fact facing decisions about the kinds of treatments or procedures they may want or don’t want.”

Beth Goddard, APRN, AOCNP, a nurse practitioner at Dana-Farber Gastrointestinal Cancer Treatment Center, said she was introduced to the conversation guide when she agreed to participate in the research protocol. An oncology nurse for more than 20 years, Goddard has a great deal of experience with end-of-life care conversations—and she believes the conversation guide improves the experience for patients and clinicians alike.

“It kind of levels the field so that you can have these conversations openly, and generally people are relieved to be able to share their thoughts,” she said.

The questions are open-ended and thought-provoking, rather than probing for a specific decision.

“The conversation facilitates an understanding of the patients and their priorities, how they have led their lives, and what they worry about in their dying process,” Goddard said. “It’s not just to get ‘Yes, I want to be DNR,’ or ‘I don’t want any more experimental treatments.’ It’s much more heartfelt and comprehensive than that.”

In one instance, a conversation with a patient veered to include the patient’s funeral arrangements and burial plans. While the conversation guide does not ask those questions, knowing that her patient wanted to tell her those things helped Goddard understand his wishes and made it easier to talk about treatment decisions.

Users of the conversation guide are trained to set up the conversation in a way that gives patients control and eases their anxiety. First, the clinician asks for permission to proceed with the conversation. Next, the patient is asked to share his or her understanding of his or her illness. And then patients are asked about what kind of information they want to receive.

On average, the conversations take about 20 minutes. Clinicians have reported that lack of time is a challenge, Paladino said, which suggests that fully integrating this approach to care requires systems support.

“We are learning that this conversation has significant value and meaning for clinicians and their patients. It’s clear we need to do a better job of prioritizing these conversations and creating an environment where these discussions are the norm for seriously ill patients.”

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## Serious Illness Conversation Guide

- What is your understanding now of where you are with your illness?
- How much information about what is likely to be ahead with your illness would you like from me? (Some patients like to know about time; others like to know what to expect, others like to know both.)
  - If your health situation worsens, what are your most important goals?
  - What are your biggest fears and worries about the future with your health?
  - What abilities are so critical to your life that you can’t imagine living without them?
  - If you become sicker, how much are you willing to go through for the possibility of gaining more time?
  - How much does your family know about your priorities and wishes?

Source: Ariadne Labs