Communicating with Patients on Treatment Options for Advanced Disease

Presented by Lillie D. Shockney RN, BS, MAS, and Anthony Back, MD

Abstract
A diagnosis of advanced cancer is devastating to patients and their families. The cancer care team has typically been ineffective in communicating honestly but sensitively on issues of concern, including treatment options, prognosis, and factors that affect quality-of-life. In a presentation at the NCCN 18th Annual Conference, palliative care experts Dr. Anthony Back and Ms. Lillie D. Shockney discussed the challenge of communicating about advanced disease, offered a new paradigm, and described approaches that can make physicians and nurses more comfortable and more effective in this role. (JNCCN 2013;11: 684–686)

“It is very unfortunate to be looking at a jaundiced 85-year-old with metastatic cancer for whom there has been no conversation at all about end-of-life,” said Lillie D. Shockney, RN, BS, MAS, Distinguished Service Associate Professor of Surgery, Oncology, Gynecology, and Obstetrics at Johns Hopkins University in Baltimore, Maryland.

“The best care engages patients—at the level of their story, their values, their families—in ways that amplify their resilience,” added Anthony Back, MD, Professor of Medicine and Adjunct Professor in the Division of Bioethics and Humanities at the University of Washington School of Medicine, and Director of the Program on Cancer Communication at Seattle Cancer Care Alliance in Seattle, Washington.

Dr. Back and Ms. Shockney discussed the challenge of talking with patients with advanced cancer and suggested ways in which such conversations can facilitate decision-making and enhance quality of life. This task requires providers to be open yet delicate with patient and respectful of their choices. It is often a task that is handled poorly, and at times, not handled at all, they said.

When the Goals of Treatment Change
Research has shown that 1) patients do want to know the truth; 2) providers can generally make forecasts with some accuracy regarding time frame for end of life; 3) an honest conversation does not rob patients of their hope or trigger depression; and 4) being truthful does not hasten death, according to Ms. Shockney, who has been the administrative director of the Johns Hopkins Breast Center since 1997 and is a 2-time breast cancer survivor herself. She has also served as the director of the Johns Hopkins Cancer Survivorship Programs since November 2011.

“When the goals of treatment change, this can be a confusing time for patients and families. But we also need to emphasize to ourselves, as well, that the goal is no longer curative,” she said. “Treatment for treatment’s sake should never be a goal,” she stated.

The health care provider should make the patient aware of the treatment options and that these decisions will be made with patients rather than for them. Importantly, this conversation should take into account the patient’s own goals. “Is it to see a grandchild born in
Dr. Back noted that communicating with patients with advanced disease is “a multipronged challenge,” because the involved parties come from different points of view. The patient says, “Don’t talk to me about anything negative,” and “I can do more” (while his wife shakes her head). His oncologist says, “I don’t think he’s ready for the conversation” and “I don’t have time for it.” His primary nurse worries, “He’s running out of time to take that trip,” and wonders, “I’m not sure if it’s ok for me to raise this issue.”

The result of this disconnect is often that the patient lives for 1 week in hospice care, and the oncology team largely “checks out,” Dr. Back continued. The oncologist laments that the patient did not respond to third-line chemotherapy. And the nurse acknowledges that while this pattern repeats itself, it may be “the best we could do,” Dr. Back said.

A Needed Paradigm Shift

These scenarios indicate that the current approach is failing in a number of ways. First, patients with incurable cancer often perceive their prognosis inaccurately. In a recent study of 1193 patients who received chemotherapy for newly diagnosed metastatic cancer, 69% with lung cancer and 81% with colorectal cancer did not understand that their chemotherapy was unlikely to cure them. Second, few patients have access to early integrated palliative care, despite the fact that a landmark study showed it prolonged life by almost 2 months and was associated with higher quality-of-life scores. Third, training in communications skills is largely not evidence-based, and system infrastructures fail to capture data, display progress, or prompt clinicians about end-of-life care planning, Dr. Back noted.

Dr. Back emphasized the need for paradigm shifts. The first is to move from “the patient is resistant” to “I can use a toolbox of skills to cultivate trust.” The “toolbox” is essentially a “map of best care” that contains options, their pros and cons, and prognosis, all developed as a skill set and communicated in a way that reinforces the positive. The second is to move from an attitude of “I don’t have time” to “I’ll do my share as part of the team.” This requires skills deployed across the care system (or care team) and positive reinforcement for outcomes that the patients and families value.

Figure 1 Steps to facilitate discussions with patients with advanced cancer. Courtesy of Tom Smith, MD, Johns Hopkins.
Accomplishing the New Paradigm

Dr. Back suggested that clinicians approach patients by knowing, before the encounter, what the clinician is trying to accomplish and by settling on 2 key points to convey to the patient. Good opening lines include, “Here’s what I had in mind for today,” and “Do you have things for our agenda?”

In presenting the pros and cons of the options, he suggested what he called double framing. In double framing, the oncologist might say, “with this option, 30 of 100 patients would have their cancer shrink for a few months, but another way of saying that is that 70 of 100 would have their cancer grow or just stay the same.” This is a way of minimizing providers’ biases, which may be largely unconscious, he pointed out.

Using “best case, worst case” scenarios can be helpful for explaining the situation accurately to the patient, he said. And he cautioned that “best case” examples should be outcomes the clinician has seen at least a few times. The clinicians should listen for the patient’s language and use it, adding statistics if the patient seems to want them.

Start with decisions that are easier to make, Dr. Back advised, then move to the more difficult ones. Remember, however, that working memory holds only a few items at a time, “and your patient is working under stress.” In other words, the conversation should be carefully paced.

Finally, patients and families need reinforcement for any of their current actions and behaviors that may be constructive. A comment such as “I appreciate your willingness to have a frank talk today—it makes for better decisions,” can be powerful and can enhance future conversations, he said.

References