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Illness Is Personal!

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For clinicians and health service researchers striving to improve care for people living with life-threatening conditions, September was a sobering month. The Dartmouth Atlas group released a brief report on *Trends in Cancer Care Near the End of Life*1 showing that while the proportion of patients with cancer who die in hospitals slightly decreased between 2003–2007 and 2010, patients in 2010 were more likely to receive life-sustaining treatments, spend time in an ICU in the final month of life, or undergo chemotherapy during the last 2 weeks of life (see related news item below). Moreover, while hospice use is up, many cancer patients are receiving hospice care only at the brink of death, for the last 3 to 7 days of life.

Two weeks later, the Institute of Medicine published a 360-page report on *Delivering High Quality Cancer Care*, which was subtitled, *Charting a New Course for a System in Crisis*.2 This report details ongoing patterns of excessive disease treatments coupled with insufficient attention to cancer patients' and their families' comfort, social support, and well-being.

Buyer Beware

Cancer care statistics and data tables are deliberately anonymous, yet the people whose stories the facts and figures represent all had names and faces, feelings and families.

Anyone who has cancer—or loves someone who has it—knows that cancer is profoundly personal. From the moment the test results come back and a doctor utters the words, "I'm afraid you have cancer," people's worlds are shaken. Getting the best care becomes Job 1. These days, that entails finding the best doctors and cancer centers in the area, searching the Internet for treatment options, and seeking second (and sometimes third and fourth) opinions.

Without notice and, in most cases, without preparation, the diagnosis turns patients and their families into "consumers" of health care. (I dislike the term, but it seems apt for the choices people with cancer must make.) Becoming an effective, discriminating consumer is essential because, as the graphs and data tables show, habits of medical practice vary dramatically from one region of the country to another—and even from one medical center to another within large cities. These regional and institutional practice patterns bias the types of care people receive, without their knowledge, and often in ways they would not want. Note to health-care consumers: Let the buyer beware.

As a doctor who has helped care for people with advanced cancer for over 30 years, when my own relatives or personal friends are wrestling with treatment decisions and turn to me for advice, here is the perspective I offer.

First, if you have a curable or highly treatable cancer, go for it! Get the best treatments you can and, within reason, stick with the program through predictably difficult times. Advances in oncology have made many of today's treatments well worth the effort.

More Is Not Always Better

However, if and when your cancer advances despite treatments and you find your strength, energy, appetite, and overall stamina are waning, be cautious about excessive medical care. The long-standing assumption is that the more diagnostic tests and treatments patients receive, the better off they will be. However, 2 decades of studies by Dartmouth Atlas researchers have proven that this supposition is often wrong.3

In advanced illnesses, including cancer, higher levels of medical treatments are commonly associated with more suffering but little or no extension of life. Yet when a person—someone's mother or father, spouse, sibling, or child—is getting sicker, the desire to *do something* is strong. Under the influence of the *more-is-better* mentality, well-intentioned clinicians and loving families can inadvertently cause people to spend precious, fleeting days at the end of a long illness in hospitals and ICUs, instead of at home or other places they would rather be.

Palliative Care, Hospice Can Extend Life

Don't confuse palliative and hospice care with giving up hope of living longer. In actuality, patients with invasive cancers who receive palliative care along with cancer treatments tend to enjoy better quality of life and *live longer.*4,5 Similarly, cancer patients who receive hospice care tend to live longer than those who don't.6

The reasons are not mysterious. Palliative care and hospice teams provide meticulous clinical attention to people's pain and other symptoms, basic bodily needs (such as eating, sleeping, eliminating, washing, grooming, and getting around), as well as support for their emotional and spiritual concerns. It's little wonder that people with advanced cancer who receive such comprehensive whole-person care are able to feel a bit better and survive longer.

Since Cancer Is Personal, So Is Cancer Care

The best care helps people live as comfortably and fully as possible through the very end of life. It supports people in the difficult but normal tasks of completing their affairs and relationships—including, if they wish, taking stock of their lives, telling their stories, and leaving a legacy to those they leave behind.

The Institute of Medicine, American Cancer Society, and American Society of Clinical Oncology have all called for cancer care to be patient-centered and attend to the well-being of people living with cancer.7-10 Despite published clinical standards and evidence-based "best practice" treatment guidelines, progress has been slow and uneven, and much remains to be done.

The solution begins with recognizing that since cancer is personal, the "best care" must be defined one person at a time. Evidence-based treatment algorithms for specific types and stages of cancer are invaluable; however, quality requires tailoring treatments and plans of care to reflect the values, preferences, and priorities of the individual living with cancer. It takes a patient with his or her chosen family members and clinicians working together to determine the optimal plan of care at each particular point in time.

Conversations Matter

Even a single conversation about end-of-life preferences between cancer patients and their physicians has been shown to improve the chances that people will be comfortable and not burdened with extraordinary treatments during their final days.11,12 Yet many people avoid talking about dying, as if talking about it will make death more likely.

In reality, everyone knows cancer can be life-threatening. That's why getting the best care is so important. If we don't talk with our families and doctors about what we would want or not want, how are they to know? Published surveys can tell us what *most people* want as they come to the end of life, but one size does not fit all. Some people want all possible treatments to prolong life, regardless of discomfort; others set limits on the amount of discomfort and treatments they will accept. The *right choice* is one that is well considered and made by a well-informed person (and family) in collaboration with health-care professionals.

Don't Take Quality for Granted

The genuinely best doctors and medical centers have made care planning conversations and shared decision-making routine. They make it easy for people to get cutting-edge cancer treatments right along with the full services of a palliative care team. Truly excellent clinicians and health systems pay conscientious attention to transitions of care, seamlessly extending care to people's homes and support to people's family caregivers.

If you or someone you love is living with cancer, it is wise to consider your options carefully. Talk with your doctor and with the people you trust to consider what types of treatment and overall care are right for you. Check the Dartmouth Atlas website (www.dartmouthatlas.org) to learn how the region you live in and the medical centers near you compare with others. Get that second, third, or fourth opinion, including one of a palliative care specialist.

After all, this is personal. There is no reason to settle for less than the best. ■

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