



Trends in Cancer Care Near the End of Life A Dartmouth Atlas of Health Care Brief

A Report of the Dartmouth Atlas Project

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Over half a million Americans die each year from cancer.¹ While progress has been made over the last two decades in addressing patient preferences near the end of life, much more needs to be done. Most patients with cancer who are approaching the end of their lives prefer supportive care that minimizes symptoms and their days in the hospital. Unfortunately, the care patients receive does not always reflect their own preferences, but the prevailing styles of treatment in the regions and health care systems where they happen to receive cancer treatment.^{2,3}

In analyses of Medicare data that control for patient age, sex, race, tumor type, and non-cancer chronic conditions, the chances that a patient with advanced cancer died in the hospital in 2010 varied from one in eight (13%) to one in two (50%) depending on the medical center providing their care, even among National Cancer Institute-designated Cancer Centers. Similarly, the number of days patients spent in intensive care units (ICUs) in the last month of life varied more than fivefold across these centers. The chances of a patient receiving hospice care differed by a factor of five.

This Atlas Brief and the accompanying data released on the Dartmouth Atlas web site (www.dartmouthatlas.org) report the latest findings on end-of-life cancer care. Since the last Dartmouth Atlas report,⁴ the trends in end-of-life cancer care across the country have been mixed (see table).⁵ While patients are spending fewer days hospitalized in the last month of life, the number of days in ICUs has increased. Hospice days have also increased, but a growing proportion of patients begin receiving hospice services in the last three days of life, a time period often too short to provide patients the full benefit of hospice care.

Overall Change in Cancer Care

- Nationally, the percent of cancer patients dying in the hospital decreased more than four percentage points, from an average of 28.8% of patients during the period from 2003 to 2007 to 24.7% of patients in 2010. There was also a substantial increase—from 54.6% to 61.3% (more than six percentage points)—in the percent of patients who were enrolled in hospice in the last month of life.
- There was an increase of more than five percentage points in the percent of patients admitted to an ICU during the last month of life, from 23.7% to 28.8%. The percent of patients for whom hospice was initiated during the last three days of life—i.e., the percent receiving a hospice referral very close to death, indicating less opportunity for meaningful palliative care—also increased, from 8.3% to 10.9%.

- The percent of patients who saw ten or more different physicians during the last six months of their lives rose from 46.2% to 58.5%, an increase of more than twelve percentage points, suggesting that more patients may have experienced fragmented care.
- The use of potentially life-sustaining treatments—including endotracheal intubation, feeding tube placement, and cardiopulmonary resuscitation—during the last month of life remained relatively unchanged. Similarly, the average percent of patients receiving chemotherapy during the last two weeks of life was virtually unchanged.
- Most importantly, the pace of improvement was uneven and varied markedly across regions and hospitals, including academic medical centers and NCI-designated Cancer Centers. In the Rochester, New York hospital referral region, the percent of cancer patients dying in the hospital increased more than five percentage points between 2003-07 and 2010, from 25.4% to 30.5%; meanwhile, the percent experiencing death in the hospital fell nearly seven percentage points in East Long Island—from 42.5% to 35.6%—even as the rate in East Long Island remained among the nation’s highest. The percent receiving a life-sustaining procedure during the last month of life rose from about 11% to more than 16% of patients receiving their cancer care at the University of Alabama Hospital in Birmingham. During the same period at the H. Lee Moffitt Cancer Center in Tampa, Florida, the percent receiving life-sustaining treatment declined from 14.1% of patients to 8.3%.

Table. National trends in selected measures of the care of cancer patients near the end of life

Measure	2003-07	2010	Percent change, 2003-07 to 2010
Number of deaths among cancer ill patients*	235,821	212,322	-10.0%
Hospital utilization			
Percent of deaths occurring in hospital	28.8	24.7	-14.4%
Percent hospitalized, last month of life	61.3	62.2	1.5%
All hospital days per patient, last month of life	5.1	4.8	-5.2%
Percent admitted to ICU, last month of life	23.7	28.8	21.6%
ICU days per patient, last month of life	1.3	1.6	21.2%
Cancer treatment			
Percent receiving life-sustaining treatment, last month of life	9.2	9.4	3.1%
Percent receiving chemotherapy, last two weeks of life	6.0	6.0	0.7%
Supportive care			
Percent enrolled in hospice, last month of life	54.6	61.3	12.2%
Hospice days per patient, last month of life	8.7	9.1	4.3%
Percent enrolled in hospice within three days of death	8.3	10.9	30.9%
Physician utilization			
Percent seeing 10 or more physicians, last six months of life	46.2	58.5	26.8%

*The estimate for 2003-07 was created by summing a 20% sample over five individual years.

Patients with cancer want to understand their chances and treatment options and to participate in decisions about their care. This is particularly true for those with advanced cancer who need to plan their last months or weeks of life. Some patients elect to continue aggressive care aimed at prolonging life for as long as possible, but most prefer supportive measures that minimize pain and days in the hospital.^{2,3} Generally, patients want to spend as much time as possible in a home-like environment close to family and friends.

While there is increased awareness of the importance of discussing personal care preferences with cancer patients, deficiencies in communication are common. In a recent study, the majority of patients with advanced lung and colorectal cancer did not understand that chemotherapy was unlikely to cure their cancer.⁶ The good news is that patients who have end-of-life conversations with their clinicians have a greater chance of receiving the type of care they prefer.^{7,8} These discussions, especially when occurring relatively early in the course of illness, are associated with greater use of palliative care and hospice and with less aggressive end-of-life care,^{9,10} countering a general trend towards more aggressive care in the last months of life.^{11,12} High-intensity end-of-life care, by contrast, is associated with poor quality of life and of death, as well as higher costs, and, in some cases, reduced survival.^{13,14,15}

Despite the increased frequency of end-of-life discussions, cancer treatment has become more aggressive in general. It could be that some patients prefer more aggressive care, or do not fully understand—or accept—that their life expectancy is limited when expressing their preferences.^{7,8} Alternatively, end-of-life discussions may occur too late in the course of illness to have a serious impact on treatment.⁹ Previous research has also shown that regional supply of health care resources, such as hospital and intensive care beds and imaging equipment, is one driver of the intensity of care, irrespective of the patient's particular condition or illness level.^{16,17} Regardless of the cause, the findings presented in this brief suggest that there is more work to be done to ensure the wishes of cancer patients facing the end of their lives are elicited, understood, and honored.

References

1. American Cancer Society. *Cancer Facts & Figures 2013*. Atlanta: American Cancer Society; 2013.
2. Barnato AE, Herndon MB, Anthony DL, Gallagher PM, Skinner JS, Bynum JP, Fisher ES. Are regional variations in end-of-life care intensity explained by patient preferences? A study of the US Medicare population. *Med Care*. 2007 May;45(5):386-93.
3. Gallup GH Jr. Spiritual beliefs and the dying process: A report on a national survey. Conducted for the Nathan Cummings Foundation and the Fetzer Institute, 1997.
4. Goodman DC, Fisher ES, Chang CH, Morden NE, Jacobson JO, Murray K, Miesfeldt S. "Quality of end-of-life cancer care for Medicare beneficiaries: Regional and hospital-specific analyses." The Dartmouth Institute for Health Policy and Clinical Practice. November 16, 2010.
5. Teno JM, Gozalo PL, Bynum JP, Leland NE, Miller SC, Morden NE, Scupp T, Goodman DC, Mor V. Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA*. 2013 Feb 6;309(5):470-7.
6. Weeks JC, Catalano PJ, Cronin A, Finkelman MD, Mack JW, Keating NL, Schrag D. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. 2012 Oct 25;367(17):1616-25.
7. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol*. 2010 Mar 1;28(7):1203-8.
8. Wright AA, Mack JW, Kritek PA, Balboni TA, Massaro AF, Matulonis UA, Block SD, Prigerson HG. Influence of patients' preferences and treatment site on cancer patients' end-of-life care. *Cancer*. 2010 Oct 1;116(19):4656-63.
9. Mack JW, Cronin A, Taback N, Huskamp HA, Keating NL, Malin JL, Earle CC, Weeks JC. End-of-life care discussions among patients with advanced cancer: A cohort study. *Ann Intern Med*. 2012 Feb 7;156(3):204-10.
10. Mack JW, Cronin A, Keating NL, Taback N, Huskamp HA, Malin JL, Earle CC, Weeks JC. Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study. *J Clin Oncol*. 2012 Dec 10;30(35):4387-95.
11. Earle CC, Neville BA, Landrum MB, Ayanian JZ, Block SD, Weeks JC. Trends in the aggressiveness of cancer care near the end of life. *J Clin Oncol*. 2004 Jan 15;22(2):315-21.
12. Ho TH, Barbera L, Saskin R, Lu H, Neville BA, Earle CC. Trends in the aggressiveness of end-of-life cancer care in the universal health care system of Ontario, Canada. *J Clin Oncol*. 2011 Apr 20;29(12):1587-91.
13. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, Mitchell SL, Jackson VA, Block SD, Maciejewski PK, Prigerson HG. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008 Oct 8;300(14):1665-73.
14. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health care costs in the last week of life: Associations with end-of-life conversations. *Arch Intern Med*. 2009 Mar 9;169(5):480-8.
15. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010 Aug 19;363(8):733-42.
16. Pritchard RS, Fisher ES, Teno JM, Sharp SM, Reding DJ, Knaus WA, Wennberg JE, Lynn J. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. *J Am Geriatr Soc*. 1998 Oct;46(10):1242-50.
17. Mintzer DM, Zgrabbe K. On how increasing numbers of newer cancer therapies further delay referral to hospice: The increasing palliative care imperative. *Am J Hosp Palliat Care*. 2007 Apr-May;24(2):126-30.

This is Personal!

Ira Byock, MD

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 thirty 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 longstanding assumption is that the more diagnostic tests and treatments patients receive, the better off they will be. However, two decades of studies by Dartmouth Atlas researchers have proven that this

supposition is often wrong.¹ 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 and hospice can help people live longer

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*.^{2,3} Similarly, cancer patients who receive hospice care tend to live longer than those who don’t.⁴ 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 the care you need

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.⁵⁻⁸ Despite published clinical standards and evidence-based “best practice” treatment guidelines, progress has been slow and uneven and, as this Atlas Brief shows, 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.^{9,10} 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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The Dartmouth Atlas Project works to accurately describe how medical resources are distributed and used in the United States. The project offers comprehensive information and analysis about national, regional, and local markets, as well as individual hospitals and their affiliated physicians, in order to provide a basis for improving health and health systems. Through this analysis, the project has demonstrated glaring variations in how health care is delivered across the United States.

*Dedicated to the memory of
Susan Goodman Alkana, sister, poet, friend.*

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References

1. Wennberg JE, Fisher ES, Stukel TA, Skinner JS, Sharp SM, Bronner KK. Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States. *BMJ*. Mar 13 2004;328(7440):607.
2. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. Aug 19 2010;363(8):733-42.
3. Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA*. Aug 19 2009;302(7):741-49.
4. Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *J Pain Symptom Manage*. Mar 2007;33(3):238-46.
5. Field MJ, Cassell CK. *Approaching death: Improving care at the end of life*. Washington, DC: National Academy Press; 1997.
6. Cancer care during the last phase of life. *J Clin Oncol*. 1998;16(5):1986-96.
7. Smith TJ, Temin S, Alesi ER, et al. American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care. *J Clin Oncol*. Mar 10 2012;30(8):880-87.
8. Institute of Medicine. *Improving Palliative Care for Cancer: Summary and Recommendations*. 2001.
9. Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med*. Mar 9 2009;169(5):480-88.
10. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. Oct 8 2008;300(14):1665-73.