In my professional role at the National Cancer Institute (NCI), I am in frequent communication with patients who have advanced cancer and who are seeking answers. Some common questions they ask include:

- "Is there a cure for my cancer?"
- "How long can I expect to live?"
- "What options do I have?"

Patients want honest, accurate information about their prognoses so that they can prepare for the future and make informed decisions about their care. They often turn to the NCI because they are afraid of bringing it up with their oncologists or because they tried to and did not receive direct information in response. While I consider it an honor to be able to help patients navigate these deeply personal questions, I am also aware that research has shown that patients are best served by engaging in these conversations with their oncologists directly.

To address this, I wrote a report advocating end-of-life care conversations between oncologists and advanced cancer patients. This report outlines some of the harmful effects on patients when these conversations do not take place; it provides evidence of the benefits these conversations have on patients and caregivers; and it makes the case that the oncology field already has sufficient tools and structure to ensure all advanced cancer patients may have these conversations with their doctors.

Planning for All Possibilities

Advanced Cancer Patients, Oncologists, and End-of-Life Care Conversations

Executive Summary

An established challenge in research studies of advanced cancer patients is a lack of communication about end-of-life care between oncologists and their patients. Without clear prognostic information, patients do not understand the likely course of their cancer diagnoses[1,2]. Patients who do not engage in end-of-life care conversations with their doctors are more likely to pursue aggressive treatment at the end of life[9]. They are also less likely to engage in advance care planning until late in their disease and do not use hospice or supportive care until they are very near the end of life.

This report will highlight the research demonstrating the need for—and the benefits of—earlier and increased communication with patients about advanced cancer care. We will provide an overview of some of the barriers which have promoted limited and late communication between doctors and patients about dying and end-of-life care. Lastly, this report refers to current clinical models available for these conversations and provides recommendations for oncologists and hospital administrations.

Changes not just at the physician level, but also at the institutional and national level will help to doctors prioritize early and sustained conversations with their patients about end-of-life care.

Introduction

American cancer culture promotes death denial. Given the “fighting” and “warrior” language used to describe a patient’s experience with cancer, especially our infatuation with the idea of “beating the odds,” it is understandable that we experience this collective denial. It is not even an entirely unfounded perspective to take. We are living in a time of rapid and widespread progress in healthcare, especially in cancer treatment. Advancements in immunotherapy and precision medicine continue to produce potential treatment options for advanced cancers that are extending survival rates, and in some cases, producing dramatic remissions for patients who had previously had few or no effective treatment options.

At the same time, most patients with advanced cancer will die from the disease. A challenge for health care providers has been, and continues to be, preserving hope while providing patients with realistic information about their diagnosis and prognosis. Conversations between oncologists and patients about prognosis and planning for end-of-life care are an integral and under-utilized part of the cancer care system.

There is not one right or wrong way to approach advance cancer planning; each patient has unique and personal wishes when it comes to what they are looking for out of their care at the end of life. Conversations about end-of-life care for advanced cancer patients that take place early in the journey give patients time to consider their personal value system as it relates to treatment decisions; they also equip caregivers to navigate decision-making and provide support to the patient. These discussions become much more difficult with progression of the disease and treatment side effects affecting the patient's and caregivers' physical, emotional, and mental states. Waiting to have an end-of-life care conversation causes patients to make treatment decisions based on a misunderstanding of their diagnoses. Patients also delay accessing supportive care until the last days or weeks of life.

A Demonstrated Problem

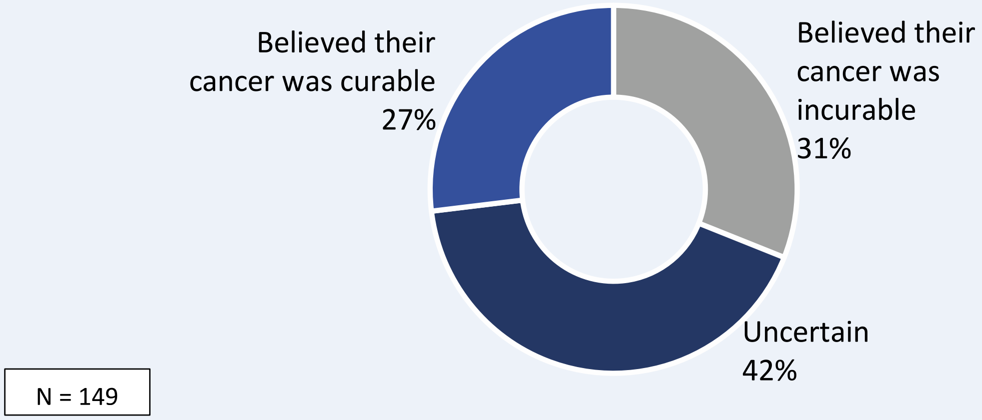
Gaps in understanding

Research has shown that cancer patients frequently misunderstand their prognoses. One study[1] asked 178 patients with advanced, refractory cancer and a life expectancy of less than six months four questions about their prognosis and the goals of their treatment. These questions assessed the patients' acknowledgment of the terminal, incurable nature of their illness; understanding that their cancer had reached an advanced stage; and recognition that they would live months as opposed to years. Of the patients sampled, only 9 were able to answer all four questions correctly. Ninety-five percent of the patients interviewed demonstrated a fundamental misunderstanding of their diagnosis.

In another study[2], 149 advanced cancer patients were assessed for their understanding of their cancer's incurability. Thirty-one percent of the patients understood their cancer was incurable, while 42% were uncertain and 27% believed their cancer was curable.

The lack of understanding exists on the physician's side as well. The multisite, observational Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)[3] looked at a sample of 4,301 seriously ill patients and their physicians. Forty-seven percent of the physicians were not aware when their patients preferred to avoid CPR.

Patients frequently misunderstand their diagnosis and therefore are not be able to make informed decisions about their care and plan for the end of life.



Understanding of prognosis among advanced cancer patients

N = 149

Late planning and implementation

Advanced directives can be written at any point in a patient's care, palliative care is available to patients throughout the cancer continuum, and hospice care is an option for patients with a six month or less life expectancy. However, researchers have found that the writing of advanced directives and implementation of supportive care often happens near death.

The SUPPORT study[3] showed that 46% of do-not-resuscitate (DNR) orders were written within 2 days of death.

According to the National Hospice and Palliative Care Organization[4], the median length of hospice care service in 2008 was 21.3 days. Another study[5] looked at a nationally representative 20% sample of Medicare beneficiaries (86,851 patients) with advanced, poor-prognosis cancers. They found that median time from advanced cancer diagnosis to death was 13 months, but these patients had a median hospice duration of just 11 days.

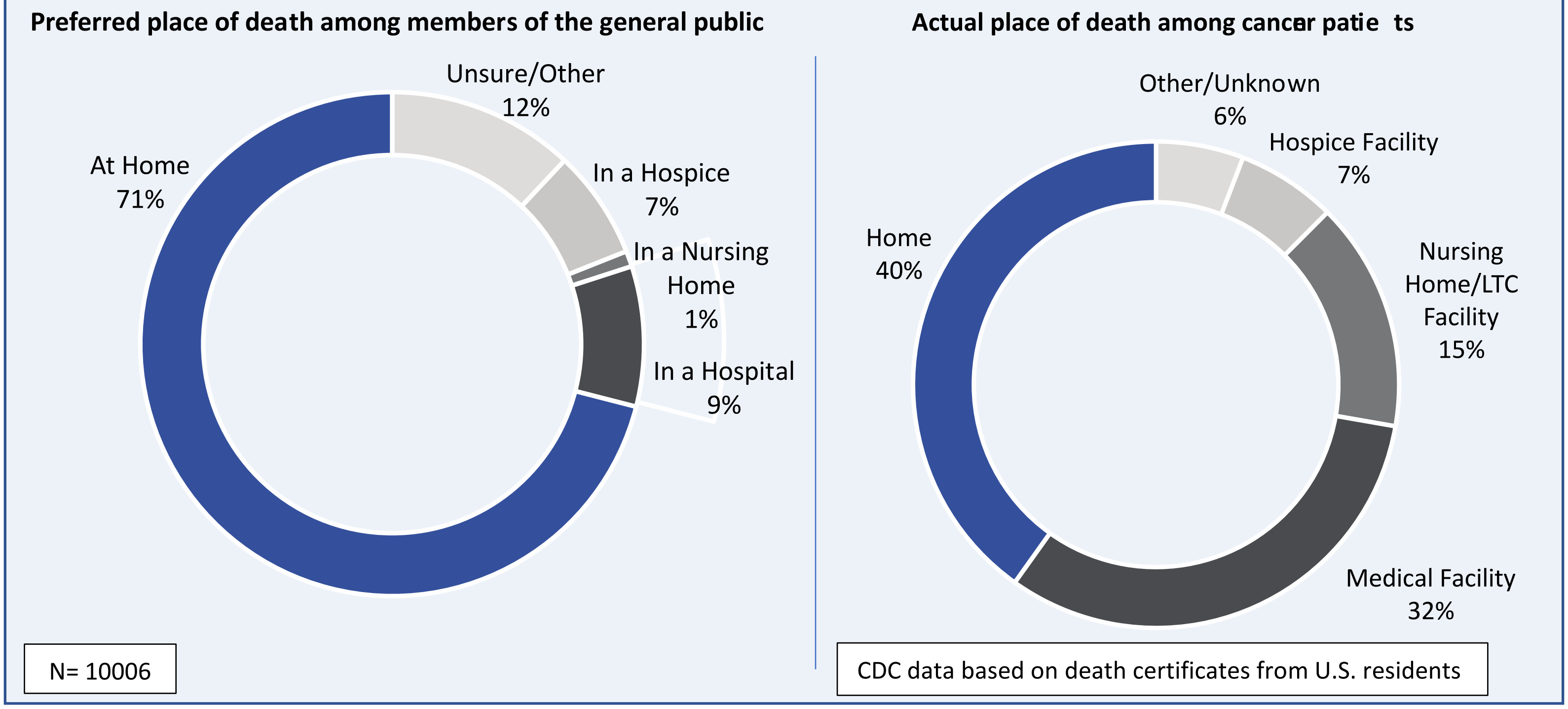
Disconnected wishes and outcomes

Each advanced cancer patient can, and should, hold their own personal preferences about their care at the end of life. End-of-life care conversations should not aim to align all individuals toward one outcome, such as hospice enrollment or exhausting treatment options. Rather, these conversations ought to empower patients to examine their own wishes and provide space for asserting those.

The reality of our current healthcare system does not align with most people's preferences. According to a meta-analysis involving 210 research studies and over 100,000 patients from 33 countries, the majority of patients wish to die at home[6]. However, an analysis of Centers for Disease Control mortality data shows that in the United States, up to 60% of cancer patients die somewhere other than their homes[7].

It has been established that conversations about prognosis between advanced cancer patients and oncologists often do not happen or take place very near the end of life. It is important to note, though, that a survey of a nationally representative sample of 1,006 Americans showed that a vast majority of individuals preferred that their physicians be completely honest about prognosis over preserving hope[8].

An overwhelming majority of patients prefer to die at home, but less than half do.



N= 10006

CDC data based on death certificates from U.S. residents

The Benefits

End-of-life conversations have been shown to improve patient outcomes. Communication about advanced cancer care decreased rates of ventilation, resuscitation, and ICU admission in a prospective, longitudinal study of 123 advanced cancer patients called the Coping with Cancer study[9]. Additionally, these conversations increase enrollment in hospice care, which is associated with increased quality of life.

An analysis of data from a study involving 1,517 patients with stage IV lung cancer showed that 26% of patients who did not discuss hospice care with a health care provider used hospice within a year of diagnosis, while 70% of those who did discuss hospice enrolled in hospice care[10]. In another multisite cohort study, researchers found that patients who reported having end of life care conversations with their doctors were more likely to be enrolled in hospice care services for longer than one week[9]. These outcomes are important because longer hospice stays are associated with better quality of life for both caregivers and patients. The same study found a correlation between hospice enrollment and improved quality of life, except among patients who did not participate in hospice care until their last week of life. The Coping with Cancer study also found greater quality of life in hospice care patients and in caregivers[9].

There is also evidence to suggest that end-of-life conversations directly improve quality of life. In one study of 481 patients with advanced cancer, being informed about a terminal illness by a doctor or caregiver resulted in significantly better quality of life compared with having guessed it based on physical symptoms or learning of the terminal status by chance[11].

Some patients may choose to pursue aggressive medical care at the end of life. However, it is important the patients be well aware of the possible risks and benefits of this approach. The Coping with Cancer study found that active treatment at the end of life is associated with worse quality of life and increased risk of major depressive disorder in bereaved caregivers[9].

Moreover, there is some evidence that palliative care may increase survival compared with aggressive treatment in terminally ill cancer patients. An assessment of 107 advanced lung cancer patients found that not only did patients who stopped active treatment to pursue palliative care experience better quality of life, they also had a median survival of 11.6 months, compared with 8.9 months in the active treatment group[12].

The Challenges

The challenges oncologists face around end-of-life care conversations are real and need to be addressed. One concern held by many physicians is that end-of-life care conversations will deprive them of hope[13]. Oncologists also cite concerns about harming their relationships with their patients as a reason these conversations often do not take place[14].

Furthermore, lack of training and tools for how to handle these conversations is another concern cited by oncologists[13]. We assert that concerns about depriving patients of hope and harming the relationship can be alleviated by providing oncologists with training in how to have effective end-of-life care conversations. In the next section, we review some of the tools that are available and which offer structured tools doctors can use to engage in these conversations in a way that supports hope while offering accurate information and provides the patient space to share in decision-making.

Clinical models

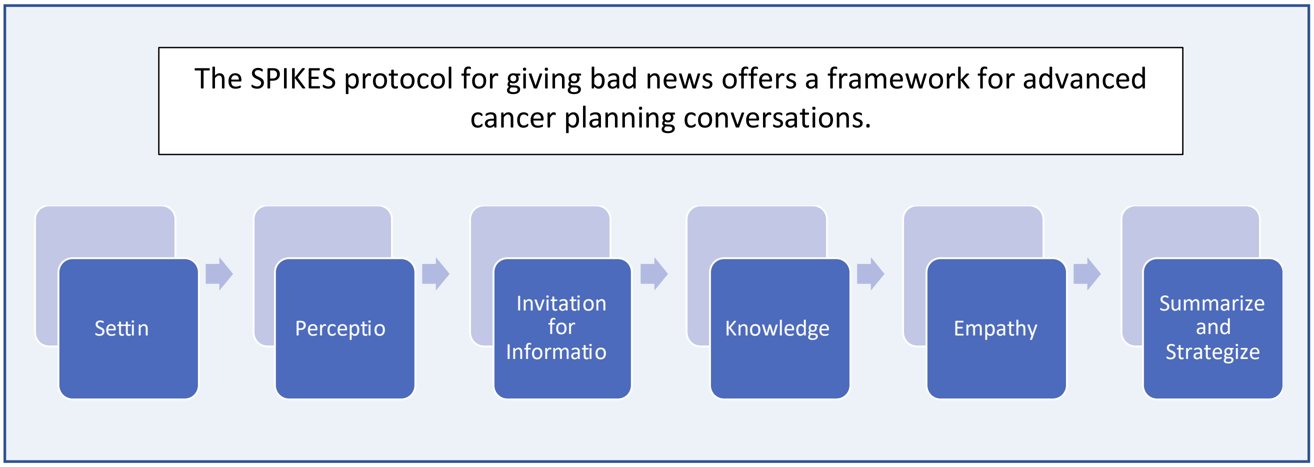
Ideally, as early advance care planning gains greater visibility and acceptance, medical schools, teaching hospitals, and continuing education providers should better teach doctors how to have these conversations. Until then, there are a variety of evidence-based resources available to oncologists to assist with these conversations.

VitalTalk

Dr. Anthony Back is an oncologist and palliative care specialist who has been at the forefront of research on the role of communication at the end of life, and he is co-founder of the clinician education organization, VitalTalk[15]. VitalTalk offers skill-building resources, videos, and structured courses designed for physicians who want to improve their communication skills around difficult topics.

SPIKES

SPIKES[16] is a structured protocol built upon previous healthcare communication research which outlines the components of an effective conversation in which bad news is delivered.


The SPIKES protocol for giving bad news offers a framework for advanced cancer planning conversations.

Ariadne Labs

Ariadne Labs is a health system innovation center that aims to create scalable solutions that improve health care delivery. Ariadne Labs' Serious Illness Care Program[17] was created by a team of palliative care experts at Ariadne Labs to address these challenges. The Serious Illness Conversation Guide includes questions to engage the patient and obtain information about goals and values. It explains how to set up the conversation, assess for understanding and preferences, offer prognostic information, check for understanding, and close the conversation.

Recommendations

Cancer centers should support and incentivize advance care planning conversations early and often for patients who have been diagnosed with advanced cancer.

As of 2016, the Centers for Medicare Services pays for advance care conversations. Institutions should ensure that all oncologists are aware of the Medicare billing codes for these conversations. Additionally, facilities should implement adherence prompts and incentives to promote widespread use of these codes among oncologists.

New and experienced oncologists should participate in continuing education training on end-of-life conversations.

Implementing training on conversations about advanced cancer early in a physician's training will emphasize the importance of skill-building in this area. Creating opportunities for continuing education will promote ongoing attention to these communication skills, as well as create a culture where these skills are expected and valued throughout the oncology community.

Advance care planning should be implemented early in a patient's advanced cancer care.

By introducing the idea of end-of-life care planning early, physicians can normalize the conversations for patients and create space to revisit patient concerns and preferences multiple times throughout the patient's experience with cancer.

Cancer centers should provide easy follow-up support for patients and their caregivers after end-of-life care conversations with their oncologists.

Oncologists also need to know that their patients will be supported following end-of-life care conversations. An established network of social workers, palliative care specialists, and patient navigators should be available throughout the process of advance care planning. Oncologists play a crucial role in educating patients and helping them make informed decisions, but they cannot be the last stop. A robust support team will result in a more positive experience for the patients and help alleviate the burden of oncologists in managing patient next steps.

For Further Research

Extreme Measures: Finding a Better Path to the End of Life by Jessica Nutik Zitter, MD
https://jessicazitter.com/extreme-measures/

Being Mortal: Medicine and What Matters in the End by Atul Gawande, MD
http://atulgawande.com/book/being-mortal/

"Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life" (2015) by the Institute of Medicine's Committee on Approaching Death
https://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near

"Implementation of Advance Care Planning in Oncology: A Review of the Literature" (2017) by Christine M. Bestvina, MD and Blase N. Polite, MD
http://ascopubs.org/doi/full/10.1200/JOP.2017.021246

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[1] Epstein AS, Prigerson HG, O'Reilly EM, Maciejewski PK. Discussions of Life Expectancy and Changes in Illness Understanding in Patients With Advanced Cancer. *Journal of Clinical Oncology*. 2016;34(20):2398 2403. doi:10.1200/jco.2015.63.6696. Accessed at http://ascopubs.org/doi/full/10.1200/JCO.2015.63.6696.

[2] Beadle GF, Yates PM, Najman JM, et al. Beliefs and practices of patients with advanced cancer: implications for communication. *British Journal of Cancer*. 2004;91(2):254-257. doi:10.1038/sj.bjc.6601950. Accessed at https://www.nature.com/articles/6601950

[3] A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA: The Journal of the American Medical Association*. 1995;274(20):1591-1598. doi:10.1001/jama.274.20.1591. Accessed at https://www.ncbi.nlm.nih.gov/pubmed/7474243

[4] National Hospice and Palliative Care Organization. NHPCO Facts and Figures: Hospice Care in America. 2009 Edition. Accessed at http://www.halcyonhospice.org/DL/NHPCO_facts_and_figures%202009.pdf.

[5] Obermeyer Z, Makar M, Abujaber S, Dominici F, Block S, Cutler DM. Association Between the Medicare Hospice Benefit and Health Care Utilization and Costs for Patients With Poor-Prognosis Cancer. *Jama*. 2014;312(18):1888. doi:10.1001/jama.2014.14950. Accessed at https://jamanetwork.com/journals/jama/fullarticle/1930818.

[6] Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care*. 2013;12(1). doi:10.1186/1472-684x-12-7. Accessed at https://www.ncbi.nlm.nih.gov/pubmed/23414145.

[7] Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2017 on CDC WONDER Online Database, released December, 2018. Data are from the Multiple Cause of Death Files, 1999-2017, as compiled from data provided by the 57 vital statistics

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jurisdictions through the Vital Statistics Cooperative Program. Accessed at http://wonder.cdc.gov/ucd-icd10.html.

[8] Hamel L, Wu B, Brodie M. Views and Experiences with End-of-Life Medical Care in the U.S. http://files.kff.org/attachment/Report-Views-and-Experiences-with-End-of-Life-Medical-Care-in-the-US. Published 2017. Accessed at https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings/.

[9] Wright AA, Zhang B, Ray A, Mack JW, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA: The Journal of the American Medical Association: The Journal of the American Medical Association*. 2008;300(14):1665-1673. doi:0.1001/jama.300.14.1665. Accessed at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2853806/

[10] Huskamp HA, Keating NL, Malin JL, et al. Discussions With Physicians About Hospice Among Patients With Metastatic Lung Cancer. *Archives of Internal Medicine*. 2009;169(10):954-962.Accessed at https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/415004

[11] Yun YH, Kwon YC, Lee MK, et al. Experiences and Attitudes of Patients With Terminal Cancer and Their Family Caregivers Toward the Disclosure of Terminal Illness. *Journal of Clinical Oncology*. 2010;28(11):1950-1957. doi:10.1200/jco.2009.22.9658.
Accessed at http://ascopubs.org/doi/full/10.1200/JCO.2009.22.9658?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%3dpubmed

[12] Temel JS, Greer JA, Muzikansky A, et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. *New England Journal of Medicine*. 2010;2010(363):733-742.
Accessed at https://www.nejm.org/doi/full/10.1056/NEJMoa1000678#t=article

[13] Granek L, Krzyzanowska MK, Tozer R, Mazzotta P. Oncologists Strategies and Barriers to Effective Communication About the End of Life. *Journal of Oncology Practice*. 2013;9(4). doi:10.1200/jop.2012.000800. http://ascopubs.org/doi/full/10.1200/jop.2012.000800.

[14] Pfeil TA, Laryionava K, Reiter-Theil S, Et al. What Keeps Oncologists From Addressing Palliative Care Early on With Incurable Cancer Patients? An Active Stance Seems Key. *The Oncologist*. 2014;20(1):56-61. doi:10.1634/theoncologist.2014-0031. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4294613/.

[15] VitalTalk. https://www.vitaltalk.org/.

[16] Baile WF. SPIKES--A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *The Oncologist*. 2000;5(4):302-311. doi:10.1634/theoncologist.5-4-302. Accessed at http://theoncologist.alphamedpress.org/content/5/4/302.long.

[17] Serious Illness Care. Ariadne Labs. http://www.ariadnelabs.org/areas-of-work/serious-illness-care/.