Issues in Focus
Perspectives on Palliative Care and Advance Care Planning

Demonstrating the Value of Innovation
Disclosure

The content of this report was prepared by Emron with the guidance of an editorial board and is based on published literature, as well as interviews of four key opinion leaders about their innovative approaches to palliative care and advance care planning. The interviewees received compensation for their participation and are not directly affiliated with Genentech. Statements and opinions contained in the report do not necessarily reflect those of Genentech or the editorial board.
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Table of Contents

Introduction ................................................................. 2
The Challenges of Delivering High-Quality Cancer Care ........................................ 2
The Continuum of Cancer Care ........................................... 4
Patient-Centered Cancer Care ............................................. 5
Shared Decision Making in Cancer ........................................ 5
Integrating Palliative Care Across the Cancer Care Continuum ......................... 8
Settings for Palliative Care .................................................. 10
Case Study: Sutter Health’s Advanced Illness Management Program ............. 12
Oncology Medical Homes .................................................. 12
Case Study: Priority Health’s Oncology Medical Home Initiative ............... 14
Assessing Palliative Care Needs ........................................................................ 14
Case Study: Respecting Choices® Program at Gundersen Health System ........ 16
Hospice: A Critical, Often Underused Component of End-of-Life Care ......... 17
Case Study: Aetna Compassionate Care ProgramSM ..................................... 18
Coverage of Palliative and Hospice Care ......................................................... 20
Summary ........................................................................... 21
Appendix .............................................................................. 22
Palliative Care Screening Tools ........................................................................ 22
Resources Promoting Conversations Between Providers and Patients .......... 22
Resources for Patients .......................................................................... 23
Resources for Employers ........................................................................ 23
Improving the Quality of Palliative Care Programs ......................................... 23
References ........................................................................... 24

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Demonstrating the Value of Innovation
Introduction

Significant innovation in the development of combined and targeted chemotherapy regimens over the past 2 decades has resulted in more effective treatments and longer lives for people with cancer. Engaged patients are critically important in determining the best course of treatment in a high-quality cancer care delivery system that seeks to meet the needs of patients with cancer and their families throughout the continuum of care. The Institute of Medicine (IOM) recommends that the cancer care team provide patients and their families with understandable information on cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and treatment cost estimates.

Palliative care is generally underutilized across the cancer care continuum. As patient preferences for treatment are central to high-quality cancer care, this inaugural report of the Issues in Focus series sponsored by Genentech takes a closer look at the benefits, challenges, and opportunities for patient-centered communications and shared decision making as they relate to palliative care, advance care planning (ACP), and timely hospice referrals. Highlighted are experiences from four key opinion leaders in the health care industry who are engaged in initiatives supporting quality in palliative care and ACP. The interviewees offered a number of resources they and/or their organizations have found helpful, which are listed in the Appendix beginning on page 22.

The Challenges of Delivering High-Quality Cancer Care

Health care quality and affordability have become pressing issues in the United States. The current fragmented health system is unsustainable in light of population demographics, health risks, and cost trends. Health care reform under the Affordable Care Act seeks to expand access to care, improve quality, and contain costs by reducing waste and pursuing value supported by evidence. The 2013 IOM report, Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis, which reviewed progress toward recommendations made in its 1999 transformative report, noted that cancer care is often not as patient-centered, accessible, coordinated, or evidence-based as it could be.

Promoting Innovation in Palliative Care and Advance Care Planning

In May 2014, Emron interviewed four champions of a systems approach to improving care for patients with advanced illness consistent with their preferences. The interviewees described their innovative programs and offered their perspectives on the importance of shared decision making through the integration of palliative care and advance care planning across the cancer care continuum.

John Fox, MD, Senior Medical Director and Associate Vice President, Medical Affairs, Priority Health

Dr. Fox spearheads collaborative opportunities with providers to advance Triple Aim goals and is engaged in care delivery redesign and payment reform strategies, including medical home initiatives. Priority Health developed and has implemented an oncology medical home collaborative project that incorporates advance care planning to improve patient experience and health outcomes, and deliver care that is consistent with patient preferences.

Bernard Hammes, PhD, Director of Medical Humanities and Respecting Choices®, Gundersen Health System

Dr. Hammes is a clinical ethicist who started the Respecting Choices®: Advance Care Planning program 20 years ago in LaCrosse, Wisconsin, to improve the prevalence and quality of informed planning by patients with life-limiting illnesses. Now internationally recognized, this evidence-based program enables an ongoing process of communication consistent with a person’s health status. Its systems approach includes community engagement, professional education, and organization/community standards of practice.

Randall Krakauer, MD, FACP, FACR, Aetna Vice President and National Medical Director for Medical Strategy

Dr. Krakauer is a champion of Aetna’s Compassionate Care program and led the design and launch of its Medicare component as a quality initiative in 2004. The program deploys Aetna’s nationally recognized expertise in case management to address issues for its members facing the advanced stages of illness and to coordinate care that demonstrably makes life better for them and their families.

Brad Stuart, MD, Chief Executive Officer, ACIStrategies; former Chief Medical Officer, Sutter Care at Home

Dr. Stuart created the first Advanced Illness Management (AIM) program in the United States, and shepherded its growth over a decade at Sutter Health with a grant rewarding excellence in end-of-life care from the Robert Wood Johnson Foundation and a $13 million health care innovation award from the Center for Medicare & Medicaid Innovation. His current pursuits at ACIStrategies leverage his experiences as a palliative care and hospice physician to promote system redesign and creation of a national standard and metrics for person-directed, value-driven care in advanced stages of illness.
The growing demand for cancer care, combined with the complexity of the disease and its treatment, a shrinking workforce, and rising costs, constitute a crisis in cancer care delivery. Particularly difficult issues facing oncology, especially in this era of health care reform, include:

- Lack of access to care
- Fragmented care
- Variations in care
- Overutilization of complex imaging, radiation, and drug treatments
- The evolving role of expensive new diagnostic tests and targeted therapies
- The need for more appropriate palliative and end-of-life care

The 2014 Genentech Oncology Trend Report found that when asked to identify the most significant gap in cancer care from among the issues presented in Figure 1, a number of respondents across the surveyed stakeholder groups chose advance care planning.

Figure 1. The Most Significant Gap in Cancer Care Identified by Key Stakeholders

Advance care planning is a process of communication between individuals and their health care agents to understand, reflect on, discuss and plan for future health care decisions for a time when individuals are not able to make their own health care decisions.

MCO = managed care organization; SPP = specialty pharmacy provider; OPM = oncology practice manager; HIT = health information technology; FFS = fee for service. Advance care planning refers to end-of-life and palliative care; treatment standardization refers to guidelines and pathways; personalization refers to molecular and biomarker testing; patient engagement refers to wellness, prevention, and medical treatment.
The Continuum of Cancer Care

To help address the challenges associated with cancer care, it is important to integrate patient-centered treatment protocols across the entire spectrum of the disease. The cancer care continuum, as addressed in this report, extends from diagnosis to end-of-life care. Each of the steps of care delivery offers an opportunity to improve the quality of cancer care, as do transitions between types of care (e.g., from active treatment to hospice care).²

During each of three overlapping phases of cancer care—acute, chronic, and end-of-life—patients may benefit from care planning, palliative care, psychosocial support, prevention and management of long-term and late effects, and family caregiver support.²

Trends in End-of-Life Cancer Care

Based on analyses published in 2013, information from the Dartmouth Atlas Project illustrates changes in end-of-life cancer care in 2010 compared with the period from 2003 to 2007 (Table 1). While patients are spending fewer days hospitalized in the last month of life, the number of days in intensive care units (ICUs) has increased. Hospice days have also increased, but a growing proportion of patients begin receiving hospice services in the last 3 days of life, a time period often too short to provide patients the full benefit of hospice care.²

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<thead>
<tr>
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<tbody>
<tr>
<td>Hospital utilization</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of deaths occurring in the hospital</td>
<td>28.8%</td>
<td>24.7%</td>
<td>-14.4%</td>
</tr>
<tr>
<td>Percentage of patients hospitalized, last month of life</td>
<td>61.3%</td>
<td>62.2%</td>
<td>1.5%</td>
</tr>
<tr>
<td>All hospital days per patient, last month of life</td>
<td>5.1 days</td>
<td>4.8 days</td>
<td>-5.2%</td>
</tr>
<tr>
<td>Percentage of patients admitted to intensive care unit (ICU), last month of life</td>
<td>23.7%</td>
<td>28.8%</td>
<td>21.6%</td>
</tr>
<tr>
<td>ICU days per patient, last month of life</td>
<td>1.3 days</td>
<td>1.6 days</td>
<td>21.2%</td>
</tr>
<tr>
<td>Cancer treatment</td>
<td></td>
<td></td>
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<tr>
<td>Percentage of patients receiving life-sustaining treatment, last month of life</td>
<td>9.2%</td>
<td>9.4%</td>
<td>3.1%</td>
</tr>
<tr>
<td>Percentage of patients receiving chemotherapy, last 2 weeks of life</td>
<td>6.0%</td>
<td>6.0%</td>
<td>0.7%</td>
</tr>
<tr>
<td>Supportive care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of patients enrolled in hospice, last month of life</td>
<td>54.6%</td>
<td>61.3%</td>
<td>12.2%</td>
</tr>
<tr>
<td>Hospice days per patient, last month of life</td>
<td>8.7 days</td>
<td>9.1 days</td>
<td>4.3%</td>
</tr>
<tr>
<td>Percentage of patients enrolled in hospice within 3 days of death</td>
<td>8.3%</td>
<td>10.9%</td>
<td>30.9%</td>
</tr>
<tr>
<td>Physician utilization</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of patients seeing 10 or more physicians, last 6 months of life</td>
<td>46.2%</td>
<td>58.5%</td>
<td>26.8%</td>
</tr>
</tbody>
</table>

Cancer Treatment at the End of Life

A recent study found that the use of palliative chemotherapy in terminal patients to ease symptoms and prolong survival was associated with an increased risk of dying in an ICU, a decreased likelihood of dying at home, and a lower likelihood that patients died in their preferred place.⁹ The American Society of Clinical Oncology (ASCO) acknowledges that there comes a point when standard oncology care is counterproductive. ASCO participates in the Choosing Wisely® campaign and annually identifies five practices that are in common use despite the absence of clinical value (see Appendix for a description of the Choosing Wisely campaign). In 2012, one of the five recommendations was to avoid unnecessary anticancer therapy, including chemotherapy, in patients with advanced solid-tumor cancers who are unlikely to benefit, and instead focus on symptom relief and palliative care.¹⁰

One of the five recommendations by the American Academy of Hospice and Palliative Medicine was not to delay palliative care for a patient with serious illness who has physical, psychological, social, or spiritual distress because they are pursuing disease-directed treatment.⁸
Patient-Centered Cancer Care

According to the IOM, a high-quality cancer care delivery system would consist of six components, with patients at the center (Figure 2). The top priority is achieving a system that supports patient decision making, followed by an adequately staffed, trained, and coordinated workforce; evidence-based cancer care; a learning health care information technology system; the translation of evidence into practice; measurement of outcomes; performance improvement; and, finally, accessible and affordable high-quality cancer care.

Integrating Comprehensive Cancer Care Plans Into Patient-Centered Treatment

Patient-centered cancer treatment planning necessitates developing an accurate, well-conceived treatment plan using all available medical information appropriately, while also considering the medical, social, and cultural needs and desires of the patient and his or her family. A treatment plan is a written document that informs everyone—the patient, his or her family, and other treating physicians—about the path of care and who is responsible for each portion of that care. It may entail a prognostic and therapeutic plan at the time of initial diagnosis, which can be updated with changes during the course of treatment, as well as a prognostic and palliative care plan near the end of life.

An amendment to the Social Security Act titled Planning Actively for Cancer Treatment (PACT) Act was introduced in the House of Representatives in June 2013. It would provide coverage of cancer care planning and coordination under the Medicare program, thereby encouraging patient involvement in written care plans. Widely supported, it remains in the Subcommittee for Health.

A cancer treatment plan can provide a roadmap, even in the final stages of cancer when treatment might only be palliative.

Shared Decision Making in Cancer

The health benefits and cost savings demonstrated when patients are actively involved in shared decision making about their health care has been well documented. However, the gap between what patients want and what they may get in terms of engagement in health care represents a lost opportunity to achieve the Triple Aim goals of improved patient experience, improved individual and population health outcomes, and lower per-capita costs, a framework developed by the Institute for Healthcare Improvement. In general, implementation of shared decision making is low in the United States, even though engaging patients in their own medical decisions has been shown to lead to better health outcomes.

In one study, patients engaged in shared decision making had 5.3% lower medical costs, 12.5% fewer hospital admissions, and 9.9% fewer preference-sensitive surgeries than patients who received the usual level of support.
Patient-clinician communication is especially important in cancer settings because a diagnosis of cancer brings levels of stress and uncertainty, complex information, and life-altering medical decisions. Effective communication may help relieve suffering directly by enhancing the patient’s emotional well-being, and indirectly by addressing such factors as social support and adherence.17

Barriers to Patient-Centered Communication in Oncology

Patient-centered communication and shared decision making in oncology may be hindered by a number of obstacles:

- The emotional, financial, and logistical repercussions of a cancer diagnosis and the complexity of treatment options
- Patients’ limitations in health literacy and lack of experience with the health care system
- The current reimbursement system, which does not incentivize clinicians to engage in patient-centered communication and shared decision making
- Clinicians’ lack of training in communication, leading to difficulties in recognizing and responding to patients’ informational and emotional needs
- A lack of understandable and easily available information on prognosis, treatment options, likelihood of treatment responses, palliative care, psychosocial support, and the costs of cancer care

End-of-Life Discussions Between Physicians and Patients

While progress has been made over the last 2 decades in addressing patient preferences near the end of life, much more needs to be done. Research in a variety of settings supports the finding that communication is often suboptimal for patients with serious and advanced illnesses. For example, in a study of audiotaped initial oncology consultations for patients with advanced cancer, fewer than half of oncologists offered alternatives to chemotherapy as an option, only 58% of patients were informed of their life expectancy, and only 60% were made aware of the risks of further chemotherapy treatment. Such gaps in information may affect patient/family-centered outcomes, such as patient or family satisfaction, length of hospital stay, treatment intensity, and quality of life.21

Some physicians may be hesitant to give patients information about a poor prognosis associated with their cancer.21 Most physicians interviewed in one study reported they would not discuss end-of-life options with terminally ill patients who are feeling well, instead waiting for symptoms or until there are no other treatments to offer.22 However, research shows that their concerns are unfounded, as illustrated on page 7.22 Earlier discussions may help to ensure that care at the end of life is more consistent with patients’ preferences.

“Through my work as an educator and clinical ethicist at Gundersen in the early 1980s, I observed our health system frequently led health professionals and families into moral distress because they did not know what patients or their loved ones wanted prior to the end of life.”

— Dr. Bud Hammes

Palliative care teams have the role and credibility to assist patients and their families manage symptoms, discuss goals of care, and make informed treatment decisions, which is distinct from that of oncologists. Patients expect them to focus on
Encouraging Discussions About Prognosis Between Patients and Physicians

<table>
<thead>
<tr>
<th>REALITY</th>
<th>MISCONCEPTION</th>
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<tbody>
<tr>
<td>It will make people depressed</td>
<td>Giving patients honest information may allow them and their caregivers to cope</td>
</tr>
<tr>
<td></td>
<td>with illness better</td>
</tr>
<tr>
<td>It will take away hope</td>
<td>Evidence suggests that hope is maintained even with truthful discussions that</td>
</tr>
<tr>
<td></td>
<td>teach the patient that there is no chance of cure</td>
</tr>
<tr>
<td>Involvement of hospice or palliative care will reduce survival</td>
<td>Multiple studies suggest that survival is equal or better with hospice or palliative care</td>
</tr>
<tr>
<td>Physicians do not really know a patient’s prognosis</td>
<td>Physicians are often able to formulate a reasonable prognosis or range of</td>
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<tr>
<td></td>
<td>possible outcomes that can bring the patient’s understanding closer to the</td>
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<tr>
<td></td>
<td>truth</td>
</tr>
<tr>
<td>Physicians tend to give the least honest figures to those with the</td>
<td>Knowledge of different preferences by ethnicity should not dictate</td>
</tr>
<tr>
<td>worst prognoses</td>
<td>communication with individuals</td>
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<tr>
<td></td>
<td>Physicians who want to know their patients’ preferences for prognostic</td>
</tr>
<tr>
<td></td>
<td>information should ask</td>
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<tr>
<td>Talking about prognosis is not culturally appropriate</td>
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<td></td>
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<tr>
<td>Physicians do not like to have these discussions and feel they are</td>
<td>Honest conversation should be a fundamental duty, and physicians should</td>
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<tr>
<td>stressful</td>
<td>remember that their patients want to have these conversations, difficult as</td>
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<td>they are for all involved</td>
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Directing cancer therapy, stabilizing disease, and prolonging life. At times, patients and their families may not express their concerns about symptoms, disease burden, and an uncertain future for fear that the oncology team may abandon them. Having a relationship with palliative care team members, whose primary focus is on enhancing quality of life through improved symptom management and psychosocial support, provides a natural opportunity for patients and their families to clarify questions about prognosis and discuss openly their concerns, symptom burden, fears, and treatment wishes.

End-of-Life Discussions Between Patients and Their Families

The California HealthCare Foundation surveyed Californians about what a “good” death meant to them. Their preferences are telling: they said they would prefer to die naturally at home without being a burden, financially or emotionally, on their families. However, only 44% of Californians who lost a loved one in the previous 12 months reported that their loved one’s end-of-life preferences were completely followed by medical providers. A significant factor for the gap between preference and reality was that patients’ preferences were not discussed and documented before a life-threatening crisis occurred.

Initiating conversations about health, legal, financial, and end-of-life issues may be difficult, but having these conversations will help to ensure that a plan is created that accurately reflects patients’ wishes and prepares and engages those who love them.

“While there is some element of truth to adults resisting the discussion because they do not like the topic, the actual larger barrier is that people do not know how to talk about it with their family.”

— Dr. Bud Hammes
The Role of Advance Directives

The completion of advance directives by patients is an important component of a cancer care plan. These legal documents specify patients’ wishes regarding the types of care they want to receive if they are unable to make important decisions for themselves.

There are two main types of advance directives: a living will and a medical power of attorney (also known as a health care proxy, appointment of health care agent, or a durable power of attorney for health care). A living will documents patients’ wishes regarding the types of medical treatment they would like to receive, such as the use of life-sustaining equipment or artificial hydration and nutrition. A medical power of attorney is a type of advance directive that allows people to name another person to make decisions about their medical care if they are temporarily or permanently unable to communicate or make such decisions for themselves.26

Advance directives can assist in providing tailored treatment for patients and can help alleviate the stress and overwhelming emotions for both patients and their loved ones when dealing with a serious illness.26

“A lot of attention is paid to these legal documents. Practically, the actual advance directive is less relevant unless it is accompanied by a discussion with patients and their families. What is most important is the conversation. If the time comes for heroic actions and not all family members know the patient’s priorities and preferences—his or her wishes—more than likely the heroic action will occur. As a health plan, we don’t care what patients’ preferences for end-of-life care are but simply that they understand their options and make them known.” — Dr. John Fox

Integrating Palliative Care Across the Cancer Care Continuum

There are important differences between hospice care and palliative care, notably the limitations on prognosis and use of life-prolonging therapies with hospice care. In the traditional cancer care model, palliative care is instituted only after life-prolonging or curative treatment is no longer administered.2 However, as illustrated in Figure 3, a paradigm shift has occurred to approaches that integrate disease-directed therapy and palliative care, such that palliative care is given throughout the continuum of cancer care with the informed preferences of patients incorporated into individualized treatment plans.2,27

Figure 3. Domains of the Cancer Care Continuum2
The Center to Advance Palliative Care defines palliative care as specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stresses of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Advantages of Early Integration of Palliative Care

Researchers have begun to propose and test new models of co-management between oncology and palliative care to help improve symptom management, reduce psychosocial distress, and enhance treatment decision making for patients with advanced cancer across the cancer care continuum.

Several studies have shown that many patients with invasive cancers who receive palliative care along with cancer treatments tend to enjoy better quality of life and live longer. One study that compared patients diagnosed with metastatic non–small-cell lung cancer who received standard care only with those who were given palliative care—in addition to standard care—right after diagnosis showed that patients in the palliative care group lived an average of 11.6 months, while those in the standard care-only group lived less than 9 months.

Early palliative care intervention can help lower total spending on inpatient health care. Hospitals with specialty palliative care services have decreased lengths of stay, admissions to the ICU, and pharmacy and laboratory expenses. Similarly, palliative care in the outpatient setting has been estimated to significantly increase patient satisfaction, while reducing use of medical services and costs of medical care at the end of life.

Early outpatient palliative care achieves these savings by decreasing the need for acute care services, leading to fewer hospital admissions and emergency department visits.

As noted in the Appendix, several initiatives are under way to standardize care through palliative care guidelines and to track, measure, and evaluate programs.

Communication During Transitions to Palliative Care

When patients are transitioning from curative or life-prolonging care to more of an emphasis on palliative care, oncologists and other providers have to find a balance between giving explicit information while not overwhelming patients and being realistic while remaining hopeful.

“These conversations are hard, and physician discomfort with them is a major impediment. However, I think all oncologists should possess basic palliative care skills, which means relieving pain, shortness of breath, anxiety, depression, constipation, and nausea, as well as comfort and experience with discussions about advance directives, durable power of medical attorney, and wishes for resuscitation. Also, they should establish links to a good hospice or two and a couple of palliative care providers.” — Dr. Brad Stuart

One study using scripted video vignettes demonstrated that explicit prognostic information and reassurance about nonabandonment were important to patients at the transition.
to palliative care. Another study found that patients were “afraid they would be left alone” when entering palliative care. In order to maintain hope, knowledge about treatment possibilities is important, but also the certainty that they will not be abandoned by the hospital at a later stage of the disease and the confidence to remain able to make their own decisions.

“There is a great need in advanced illness for the provision of the same type of expert professional help that we expect in other medical conditions, such as heart failure. The culture of medicine is a barrier to this. Physicians have to stop thinking about advanced illness planning as a failure on their part and realize that patients expect help to be appropriate to their condition and their actual status. They have to rethink this.” — Dr. Randall Krakauer

Another study compared the responses of patients in an advanced stage of cancer to a verbal description plus a video that depicted actual treatment options for various goals of care, versus a verbal description alone. Three levels of medical care in advanced cancer — life-prolonging care, basic medical care, and comfort care — were addressed in the verbal narrative and the video. Figure 4 illustrates that patients who were able to both hear and see information about end-of-life care options were more likely to prefer comfort care.

The question remains as to when and how often to have such conversations, which frequently depend on the type and stage of the cancer. All the interviewees agreed that a discussion about prognosis and what is likely to happen in the future should occur several times during a person’s illness. Several interviewees pointed out that cancer has visible ups and downs compared with other illnesses, such as congestive heart failure, and the first relapse should be a reminder to get palliative care involved. It is a different discussion when the cancer has progressed beyond first and second lines of chemotherapy. If a third line is being considered, most people generally only have weeks to months to live. These automatic triggers should alert physicians to the need for additional conversations.

“We should frame our conversations as: “We are going to hope for the best, but prepare for the worst. So we should really pay some attention to planning right now, not only for the best treatment we can give you, but to help you settle issues important to you.”” — Dr. Brad Stuart

Settings for Palliative Care

Nonhospice palliative care specialty services are most commonly provided in the inpatient hospital setting for patients with serious and/or life-limiting illnesses. However, specialty services in other settings (eg, clinic, home) are increasing nationwide to better meet the needs of patients, families, and health care providers across the entire disease trajectory and continuum of care settings. Such services allow earlier and more consistent involvement of palliative care clinicians to serve patients and to provide care following discharge for patients seen by an inpatient palliative care consultation service. Palliative care in settings outside the hospital is likely to be a major component of health system designs that include patient-centered medical homes and other care delivery systems.

Inpatient Palliative Care

Many hospitals and health care systems have recognized these benefits and are moving in a coordinated fashion to integrate palliative care principles and services. These services help meet national priorities of providing high-quality, patient-centered care and reducing readmissions and health care costs.

Figure 4. Goals-of-Care Preferences for Patients With Advanced Cancer in the Verbal and Verbal Plus Video Groups

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<thead>
<tr>
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<th>Comfort care</th>
<th>Basic medical care</th>
<th>Life-prolonging care</th>
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<tbody>
<tr>
<td>Verbal Only</td>
<td>51.9%</td>
<td>25.9%</td>
<td>22.2%</td>
</tr>
<tr>
<td>Verbal + Video</td>
<td>91.3%</td>
<td>4.4%</td>
<td>4.4%</td>
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</table>

Patients who were assigned to hear a verbal narrative of goals-of-care options at the end of life, as well as a video depicting those same options, were more likely to prefer comfort care if their cancer became very advanced than if they only listened to the verbal narrative.
The prevalence of palliative care in US hospitals with 50 or more beds increased 157.1% over 11 years, from 658 hospitals with a palliative care program in 2000, to 1,692 such programs in 2011. If current trends continue, by 2014, eight in 10 US hospitals with 50 or more beds will have a palliative care program (Figure 5). The overall prevalence of hospital palliative care (regardless of hospital bed size) is highest in the densely populated Northeast (74%) and lowest in the South (42%).

**Palliative care team:** Specialist palliative care services should be delivered by an interdisciplinary team that includes physicians, advanced practice providers, nurses, clinical pharmacists, social workers, nutritionists, spiritual counselors, and others with special training and, if possible, with certification. Some hospitals have established full-fledged programs within departments, while others include teams who work in other areas of the hospital. The palliative care team manages referrals, triages additional services, and coordinates discharge planning, while working in tandem with other hospital staff.

**Palliative care consultations:** Though a physician consultation order is required for billing, at many hospitals, any staff or family member may request a palliative care consultation.

“In palliative care services and advanced illness management programs, it is critical to engage and support the referring physician. They should stay in control of care. You will have much better clinical and financial outcomes if you can successfully engage the physician, the person, and the family. Plus, as physicians get more engaged with this kind of care, you’ll see rapid change in medical culture regarding advanced illness and the end of life.”

—Dr. Brad Stuart

**Integration into the ICU and ED:** The ICU and the ED provide care for the sickest patients and are often where major decisions are made concerning appropriate levels of medical intervention. To help clinicians, patients, and families, some ICUs and EDs are working in partnership with palliative care staff to develop collaborative practice models that seek to infuse palliative care principles and goal-setting practices into the daily care of patients and families.

**Leveraging technology:** Advance directives and code status can be documented in the electronic medical record. Reminders to conduct standardized assessments, such as spiritual, symptom, and prognosis assessments, also may be built into the system.

**Measuring program success:** Useful metrics to measure the impact and value of hospital palliative care address various aspects of care delivery, including operational, staff productivity, processes of care, financial, and quality.

**Outpatient Palliative Care Delivery**

Despite the growing evidence supporting the effectiveness of palliative outpatient clinics, only 59% of National Cancer Institute (NCI)-designated cancer centers and 22% of non–NCI-designated cancer centers reported having such clinics.

Limited data are available on how the timing and setting of palliative care referral can affect end-of-life care. However, a recent study showed that patients who were referred to outpatient palliative care had improved end-of-life care compared with those who were first referred as inpatients. Specifically, outpatient referral was associated with significantly fewer ED visits, hospital admissions, hospital deaths, ICU admissions, and a shorter duration of hospital stay in the last 30 days of life.

The Center to Advance Palliative Care has described three approaches for the delivery of outpatient palliative care in hospital or health system settings:

**Stand-alone clinic** — may function similar to other specialty practices (eg, oncology clinics) with reserved office space and dedicated staff for palliative care services.
Co-located clinic — operates using space and shared services from another clinic, which is often a frequent user of palliative care services, such as an oncology clinic.

Embedded clinic — involves a defined collaborative relationship between a host clinic (eg, oncology) and the palliative care staff, with patients predominantly referred from the host clinic staff and the relationships of patient flow between the host and palliative care staff defined by clinical pathways or protocols.

Home-Based Palliative Care

Because of the parameters of the Medicare hospice benefit, home health agencies have built palliative care programs to fill unmet patient needs. Home health care can play a critical role in providing palliative care and, through innovative programs, can improve access to it. One innovative example of home health-based programs that include a palliative care component, which has been reported on in peer-reviewed literature, is Sutter Health’s Advanced Illness Management (AIM) program (see case study below).45

“There is no accepted standard model of ambulatory or home-based palliative care yet, other than advanced illness programs.” — Dr. Brad Stuart

Oncology Medical Homes

Oncologists are increasingly accountable to meet the Triple Aim goals. Despite survey findings that demonstrate essentially no variation from traditional fee-for-service

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**Case Study: Sutter Health’s Advanced Illness Management Program**

While at Sutter Health, Dr. Brad Stuart created the first Advanced Illness Management (AIM) program in the United States. His insights inform much of the following information about the program.

**Background:** In 1998, Dr. Stuart applied for and received a Robert Wood Johnson Foundation grant promoting excellence in end-of-life care to create a home care model using nurse practitioners and social workers called CHOICES — Comprehensive Home-based Options for Informed Consent about End-stage Services. When the managed Medicare population in northern California shrank drastically in reaction to payment reforms enacted around the year 2000, the program changed its focus to home health, since the majority of eligible persons were in home health and not connecting well with hospice services. The program’s scale was broadened by retraining home health nurses and social workers beyond recovery-focused home health to deliver the successful nurse practitioner-delivered CHOICES model of care. The program was renamed Advanced Illness Management (AIM) in 2002.

In mid-decade Sutter Health adopted the AIM program as a pilot and by 2010 invested in a system-wide implementation aided by a $13 million health care innovation grant from the Center for Medicare and Medicaid Innovation. Dr. Stuart reported that within a year, AIM was successfully implemented across 80% of Sutter’s geography and generating good results.

**Program description:** The AIM program began as a symptom management and care planning intervention for Medicare-eligible home health patients. Patients eligible for the program meet the following criteria45:

- Patients with clinical, functional, or nutritional decline
- Patients with multiple hospitalizations, emergency department visits, or both within the past 12 months
- Patients who are clinically eligible for hospice but have chosen to continue treatment or have not decided to enter hospice care

AIM has evolved over time to a program with an interdisciplinary focus across sites and providers of care to improve the overall outcomes for patients with advancing illness. AIM incorporates:

- A broad care management model, including principles of patient/caregiver engagement and goal setting
- Self-management techniques
- Ongoing advance care planning (ACP), symptom management, and other evidence-based practices related to care transitions and care management

“The AIM intervention automatically integrates disparate providers, such as hospitals, physician groups, home health, hospice, community agencies, and churches, into a unified system of care management. We train the care managers and equip them to stay in touch with each other at all times, and with the physician who is running the case in question.” — Dr. Brad Stuart
The AIM program includes a process of continuous ACP that starts the second patients meet with the team, whether it is in the hospital, home, or office, and continues over time through interactions in the safety and comfort of where they live and at their own pace. It is expressly designed to start with a discussion of personal goals—personal first and clinical second. In this new paradigm, it is no longer “patient-centered” care; rather it is “person-centered” attention and support.

“The team gets to know the person, not the patient, by first exploring who they are and what is important in their life. Once trust is established, the clinical goals follow naturally. It is a radical new paradigm that supports the miraculous human capacity to adapt.” — Dr. Brad Stuart

Program outcomes: Preliminary data show improved adherence to patient wishes and goals; significant reductions in unnecessary hospitalizations and inpatient direct care costs; and significant improvements in patient, family, and physician satisfaction when late-stage patients were served through AIM rather than through home care alone.

According to Dr. Stuart, early on there was a lot of resistance to lowering revenue through reduced hospital admission rates as a consequence of the AIM program. Sutter was an early adopter and saw the movement toward expanding the ambulatory side, while reducing the inpatient side of their system. Other leading organizations now adopting AIM programs are accountable care organizations, Medicare Advantage plans, and health systems that are vertically or virtually integrating.

In the progression away from fee-for-service practice, oncology medical homes allow community oncologists to work collaboratively with payers on the Triple Aim goals, since few oncology practices participate in accountable care organizations (Figure 6) (see the case study on page 14).

“In a top-to-bottom financial analysis of AIM, there are system-level and payer-level costs to consider, and the risk equation is extremely important. As health care reimbursement moves from fee for service toward global risk, savings from AIM programs go straight to the providers’ bottom line. These programs will make more and more financial sense as these new payment models evolve.”

— Dr. Brad Stuart

“These are the early days, so there are the usual barriers to surmount. New programs must be scalable and sustainable to justify investment by systems and health plans. Now that we are figuring these things out, we are seeing rapid progress by leading systems toward a national model of care for advanced illness.”

— Dr. Brad Stuart

reimbursement methodologies in oncology, the commercial health insurance sector is quite actively pursuing nontraditional and innovative methodologies in payment redesign for oncology services, typically at the community oncology level. These tend to focus on drug cost reduction achieved through compliance with clinical pathways. The predominant model has been to compensate oncologists at a premium for compliance with agreed-on clinical pathways.

In the progression away from fee-for-service practice, oncology medical homes (OMHs) allow community oncologists to work collaboratively with payers on the Triple Aim goals, since few oncology practices participate in accountable care organizations (Figure 6) (see the case study on page 14).
Assessing Palliative Care Needs

In its palliative care clinical guidelines, the National Comprehensive Cancer Network (NCCN) provides a framework for the ongoing assessment of palliative care needs and facilitates decision making as to when referral to palliative care services may be appropriate (see Appendix for several palliative care screening tools). 48

All cancer patients should be screened for palliative care needs at their initial visit, at appropriate intervals, and as clinically indicated. 48

Case Study: Priority Health’s Oncology Medical Home Initiative

Dr. John Fox has been very engaged in the development and implementation of Priority Health’s oncology medical home (OMH) initiative described below.

Priority Health, a regional Michigan-based insurance carrier, in collaboration with five community-based oncology practices, Physician Resource Management and Ion Solutions, developed and implemented an OMH program in February 2012, designed to drive oncology patient care delivery redesign through the adoption of the OMH and in doing so achieve Triple Aim objectives. Currently, the program includes six practices and more than 60 physicians. 47 The program is composed of two core elements: payment reform and care delivery redesign.

Payment reform: Priority Health pays oncologists for their drug acquisition costs and a monthly care management fee for taking care of cancer patients, independent of cancer type, cancer stage, and method of drug administration. Separate care management fees are calculated for commercial patients and for Medicaid and Medicare patients. The care management fee is intended to compensate practices for ancillary services that are not typically compensated, such as patient education, psychological assessments, financial advocacy, social services assistance, and team conferences. Physician services and other cognitive services, such as genetic counseling, advance care planning, treatment planning, and medication therapy management, continue to be reimbursed as fee-for-service evaluation-and-management fees.

“We recognize that oncology practices provide a host of value-added services, which account for additional expenses for which they need to be adequately paid.”—Dr. John Fox

Care delivery redesign: To help achieve the Triple Aim goals, the oncology practices and Priority Health collaborated on care delivery redesign in three areas:

1. Preferred drug regimens
2. Advance care planning (ACP)
3. Care management, which includes standardizing the patient triage process and enhanced patient navigation

“Together, we reduce emergency department visits and hospitalizations through a campaign that supplies wristbands imprinted with the practice’s telephone number along with “Call me first, I care.” It is one thing to tell the patient to call you first, but if in a time of crisis they do not have the telephone number, it doesn’t work.”—Dr. John Fox

Practices must establish an ACP program for patients receiving chemotherapy. At a minimum this must include a facilitated discussion with patients receiving treatment for metastatic disease within 60 days of initiation of chemotherapy and prior to additional treatment for disease progression. The facilitated discussion is typically with a trained staff member—not necessarily with the physician—and the patient and family members. When ACP documents are completed, the program requires insertion into the chart and filing with the patient’s preferred hospital. This ACP component of the OMH is designed to be an early intervention with all patients

NCCN guidelines note the following clinical situations to be considered when determining the application of palliative care48:

- Uncontrolled symptoms
- Moderate to severe distress related to cancer diagnosis and therapy
- Serious comorbid physical and psychosocial conditions
- Advanced or progressive disease for which no effective curative therapy is available and/or life expectancy is 1 year or less
- The patient or family has concerns about the disease course and decision making
- The patient or family specifically requests palliative care
with metastatic cancer so that later on when palliative care physician involvement is likely needed, it isn’t the first time patients are thinking about and communicating their wishes for end-of-life care.

“Most gratifying are the stories of these discussions with patients and their families that are shared during ongoing training and support groups for the ACP facilitators. These are difficult discussions and the facilitators are very engaged and committed to their work and making a difference in the lives of patients.” — Dr. John Fox

**Physician reimbursement:** Priority Health reimburses health care providers for ACP discussion facilitation using the Healthcare Common Procedure Coding System billing code S0257 for counseling and discussion regarding advance directives or end-of-life care planning and decisions with patients and their family/surrogate. Commercial, Medicare Advantage, and managed Medicaid plans are included in coverage, and any qualified health care providers, such as nurses, psychologists, social workers, and clinical pharmacists, providing these services can bill using this code. Considered a preventive health benefit, these services are provided at no cost to patients.

“We’ve made it explicit that we value these discussions and recognize them as separate, independent, and valuable services to be paid for outside of the care management fee.” — Dr. John Fox

**Performance metrics Priority Health uses to evaluate ACP:**
- Percentage of patients offered the opportunity for an ACP discussion within 60 days of the first dose of chemotherapy
- Percentage of patients who participate in an ACP discussion

Each practice is allowed to design or select a program that best suits the practice and which includes a replicable process that ensures patients can have a facilitated discussion at the relevant time. Two resources implemented by practices within the OMH are the *Respecting Choices®* program from Gundersen Lutheran Foundation (see page 16 for a case study describing the program) and *Five Wishes®* (see Appendix for a description of the document).

“We have proven that we can move the cancer delivery needle and can change what we value in cancer care and how we pay for it, and, in doing so, improve outcomes. What is most validating is the practices’ willingness to continue the OMH model after the 2-year trial period. Even though Priority Health may be a small payer in some practices, those practices are participating because this is the right thing to do. It is a better way to provide cancer care.” — Dr. John Fox

“Distress screening tools can help identify how patients are coping with the emotional, psychological, and physical side effects of cancer treatments. When addressed, longer time on therapy and better outcomes can result.” — Dr. John Fox

Among cancer patients aged 65 and older, 36% reported at least one comorbidity, and 16% has two or more. Health conditions complicate the treatment of many cancers.

**Barriers to the Integration of Palliative Care**

Despite the positive findings from recent research and calls for increased access to palliative care services in the community, most patients who are diagnosed with metastatic disease today will not have an opportunity to obtain outpatient palliative care services. The precise model for the efficient delivery of palliative care has yet to be determined.

Key issues in the early integration of palliative care include the following:
- Relationship building across multiple health systems and specialties
Development of a standardized definition of palliative care, making clear that it should be fully integrated with cancer-directed therapy
Identification of physician and nonphysician champions
Standardization of tools for patient assessment
Education programs designed to meet the needs of health care professionals
Ongoing evaluation to assess program benefits and limitations

The Center to Advance Palliative Care notes barriers in three key areas that prevent full availability of palliative care for all patients and families facing serious or life-threatening illness and three key policy initiatives to address those barriers (Table 2). Resources supporting these policy initiatives are included in the Appendix starting on page 22.

With improving patient access to palliative care services, insurers/payers need to work with providers to reduce or defer the associated costs to patients, which can create barriers to

Case Study: Respecting Choices® Program at Gundersen Health System

Dr. Bud Hammes was instrumental in developing and implementing the Respecting Choices program at Gundersen Health System. His insights inform much of the following information. (More information about the program can be found at www.gundersenhealth.org/respecting-choices.)

Program description: Respecting Choices is an internationally recognized, evidence-based advance care planning (ACP) program, which began in 1986 for end-stage renal failure patients and was expanded to all older patients in the LaCrosse, Wisconsin, community. The program incorporates key elements of ACP and makes ACP a fluid, ongoing process of communication integrated into the routine of patient-centered care and appropriately staged to the individual’s state of health, including:

- Comfort and dignity during end-of-life care
- The patient’s participation in decisions regarding care, treatment, or services before and at the end of life
- A complete patient record reflecting the patient’s care, treatment, or services

“We tried to create a program which would increase not only the prevalence of planning but the quality of planning so that it would become the norm, that when faced with difficult and challenging moral decisions with critically ill patients, we would almost always know their preferences ahead of time.” — Dr. Bud Hammes

Program components: The program is a three-step approach to ACP because the values and goals of patients change over the course of their illness.

- First Steps planning is appropriate for all adults with the goal of motivating individuals to learn more about the importance of ACP select a health care decision maker, and complete a basic written advance directive.
- Next Steps planning is initiated for patients who have begun to experience a progression of their illness. It is delivered by trained professional facilitators who have experience with illness trajectories and related patient care and helps patients and their families understand life-sustaining treatments, including each treatment’s benefits, burdens, and alternatives.
- Last Steps planning is intended for frail elders or others whose death in the next 12 months would not be surprising. Specific and timely life-sustaining treatment decisions are made and converted to medical orders that will guide the actions of health care providers and be consistent with the goals of the individual.

“Through these three stages, we are trying to plan in an understandable way to the level of detail needed for events likely to occur given the person’s stage of illness, and identify values and goals they have in making those plans.” — Dr. Bud Hammes

Advanced disease coordination (ADC): This new model of care was introduced a few years ago at Gundersen, which blends together their palliative providers, successful care coordination program, and the Next Steps planning intervention. The ADC team creates a care plan based on patients’ values, needs, and choices to help reduce their risk of more severe health problems often caused by their disease. They are given one-on-one support each time they face new choices about how to manage their symptoms, while their primary care physician and/or specialist continue to manage their care and treatment.

“Honoring patients’ wishes starts with knowing what those preferences are, but it then requires a delivery system that can meet and achieve those preferences.” — Dr. Bud Hammes
participation in such care. According to the IOM, the Centers for Medicare and Medicaid Services (CMS) and other payers should design and evaluate new payment models that incentivize the cancer care team to provide care that is based on the best available evidence and aligns with their patients’ needs, values, and preferences.

### Palliative Care Certification/Accreditation

The benefits of palliative care have prompted the development of initiatives and programs to better support its implementation and recognize organizations that demonstrate excellent patient care and optimize quality of care for patients with serious illness. Organizations, such as the Joint Commission’s Advanced Certification Program for Palliative Care, recognize exceptional hospital inpatient palliative care programs that are led by an interdisciplinary team whose members are experts in palliative care.

The Commission on Cancer (CoC) accredits cancer programs around the country. The Cancer Program Standards 2012: Ensuring Patient-Centered Care includes Standard 2.4, which states: Palliative care services are available to patients either on site or by referral [to other facilities and/or local agencies]. CoC suggests that a palliative care team consist of at least one physician and one nonphysician, such as a nurse, pharmacist, social worker, or chaplain.

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Policy initiative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workforce</td>
<td>Invest in a trained palliative care workforce to ensure sufficient numbers of specialists to teach clinicians and provide high-quality palliative care for high-risk/complex patients</td>
</tr>
<tr>
<td>Research</td>
<td>Invest in the research necessary to establish a strong science base for palliative care and to expand its ability to improve both quality and length of life</td>
</tr>
<tr>
<td>Access and quality</td>
<td>Invest in health care system capacity by requiring delivery of high-quality palliative care in hospitals, nursing homes, and community settings through changes in measurement, payment, and accreditation standards</td>
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### Hospice: A Critical, Often Underused Component of End-of-Life Care

Hospice care is often an underutilized or ineffectively used service at the end of life. It is defined as a service delivery system that emphasizes symptom management without life-prolonging treatment and is intended to enhance the quality of life for both patients with a limited life expectancy and their families. Hospice care addresses patients’ physical, intellectual, emotional, social, and spiritual needs and facilitates autonomy.

> “Palliative care is a very important component of advanced illness management and by the same token managing the end of life through hospice care is an important component of palliative care.”

— Dr. Brad Stuart

Hospice comprises an interdisciplinary team, with members providing care as needed by the patient and/or family. Hospice care is provided by an interdisciplinary team whose members are experts in palliative care.

As of October 2012, 3,356 physicians passed the hospice and palliative medicine subspecialty board exams, which has more than doubled since the subspecialty’s inception in 2008.

In addition, more physicians and nurses are becoming certified in palliative care. Since hospice and palliative medicine became a certified specialty in 2008, an increasing number of physicians are becoming board certified. However, there remains a shortage of credentialed palliative care physicians. To fill that void, hospitalists are becoming more engaged in palliative care. In some settings, hospitalists are scheduled for palliative care shifts or have palliative care visits incorporated into daily rounds.

Hospice care is a model for quality, compassionate care for people facing a life-limiting illness or injury and is focused on caring, not curing. Hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Hospice care is a form of palliative care and occurs at the end of life.
Benefits of Hospice

Numerous studies have pointed to the benefit of hospice in improving the quality of life at the end of life. Similar to palliative care, hospice has been associated with reductions in symptom distress, improved outcomes for caregivers, high patient and family satisfaction, and cost-effectiveness.\(^{60,61}\)

One study reported that terminally ill patients with colorectal and prostate cancers who chose hospice care lived an average of 29 days longer than those without hospice. The authors concluded that a cessation of invasive medical treatments in already weakened individuals may help to prolong life, and the intervention of a hospice care

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**Case Study: Aetna Compassionate Care Program\(^{SM}\)**

Dr. Randall Krakauer proposed and championed the use of case managers, embedded in medical practices whenever possible, who receive training in the Aetna Compassionate Care Program\(^{SM}\) (ACCP) for end-of-life care. His comments inform much of the discussion on the program.

To improve the quality of patient care for individuals with life-threatening illnesses, insurers have increasingly turned to the concept of case management. In 2004, Aetna launched ACCP as a quality initiative, rather than to reduce costs.

**Program description:** ACCP uses Aetna’s case management capabilities to address key issues and make life demonstrably better for Aetna members with advanced illness. The program focuses on helping people understand pain management and other palliative (comfort) care options, and, therefore, helping to enable them to make more informed decisions about how to spend their final days. The services of ACCP are provided to Aetna members at no cost to them.

**Enhanced case management:** Aetna’s nurse case managers are trained to identify individuals who may benefit from the program and to evaluate cases in a culturally sensitive manner. They ascertain the appropriateness of the case and obtain the physician’s agreement. Then they intervene directly with members and families in collaboration with physicians. The goal is to improve all aspects of physical and emotional support, including pain management, continuity of care, advance planning, and personal assistance.

Case management is mostly by telephone, though members increasingly are being seen by case managers in their homes. The nurses also work closely with community-based services to help members during this final phase in their lives.

“There seems to be a significant value, particularly post-discharge, in doing evaluation and management in the home.” — Dr. Randall Krakauer

Some case managers are embedded in multispecialty practices, including oncology, or very large oncology practices, which allows for face-to-face time with the physicians and staff, as well as with patients during visits.

“The key ingredient to our success is selecting, training, and mentoring good case managers because these are the people who make the program work. These managers develop a close relationship with the members; it is the depth of this connection that is valued by the members and their families. These nurses find this work very rewarding.” — Dr. Randall Krakauer

**Member identification:** Members are identified in several ways: 1) using a predictive model that Aetna has developed, 2) through the process of concurrent review and precertification, 3) by member self-referrals due to program information featured in member newsletters, and 4) through physician referrals, though they comprise a small, but growing, portion of the total cases.
team's monitoring of patients, as well as their attention to emotional well-being, may give patients an increased desire to keep living. In addition, a cost-savings component may be associated with hospice care. A 2013 study compared Medicare costs for patients receiving hospice care with patients not receiving hospice care across four different periods of hospice enrollment. Results show Medicare costs for patients enrolled in hospice were significantly lower than those of nonhospice enrollees across all periods studied (Figure 8).

Challenges Associated With Hospice Care

The number of hospice facilities continues to increase. The first opened in 1974; by 2012, the number of facilities increased to 5,560. Though hospice is now accessible to most Americans, it is underutilized, and, in many cases, hospice is used for

**Physician services**: Aetna pays physicians for palliative care consultations and for any office visits or consultations with the patient on advanced illness planning. Aetna has also created a physician education program and has trained its medical directors across the country to present it at grand rounds in hospitals, at professional societies, and at medical education venues.

**Liberalization of the hospice benefit**: In 2004, Aetna liberalized its hospice benefit, with a group of commercial plan sponsors, by extending the life expectancy to 12 months and dropping the requirement that patients abjure curative therapy. Aetna indemnified these plan sponsors against any resulting increase in costs and discovered that liberalizing the benefit, along with appropriate case management, did not increase their costs. The liberalized benefit is now standard for commercial (not Medicare) medical contracts. Aetna has approached the Centers for Medicare and Medicaid Services many times for permission to liberalize the hospice benefit for its Medicare Advantage members at Aetna’s own financial risk but has not received permission.

**Program results**: Initially, only a series of outcomes from ACCP were monitored, with the following results:
- Tripling of the hospice election rate
- More than doubling of the average hospice length of stay
- 82% reduction in acute inpatient days
- 86% reduction in intensive care unit days
- 77% reduction in emergency department visits
- A high level of satisfaction among members and families

Subsequently, savings from the program were calculated because of external pressures to do so. In terms of Medicare, more than $12,500 was saved for every member engaged in ACCP.

“Aetna’s results, and comparable results from programs like Sutter and Gundersen, have been published in peer-reviewed journals for years. It is beyond the point where it should be surprising. If a drug for a medical condition produced such dramatic results, it would become the standard of care. Likewise, this care management assistance program should become the standard of care.” — Dr. Randall Krakauer

“There are few programs like this that are a win for everyone—the payer, the member, and his or her family—and reduce cost and produce satisfaction. There is no greater opportunity for impact at the intersection of quality and cost, particularly for Medicare.” — Dr. Randall Krakauer

**Figure 8. Incremental Savings in Medicare Expenditures, by Various Lengths of Hospice Enrollment Before Death With Matched Nonhospice Controls**

<table>
<thead>
<tr>
<th>Hospice enrollment range</th>
<th>Total Medicare savings ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1–7 days</td>
<td>$2,651</td>
</tr>
<tr>
<td>8–14 days</td>
<td>$5,040</td>
</tr>
<tr>
<td>15–30 days</td>
<td>$6,431</td>
</tr>
<tr>
<td>53–105 days</td>
<td>$2,561</td>
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</tbody>
</table>
just days or even hours before the patient’s imminent death to manage acute symptoms, which does not give the patient or family time to plan important events or have closure. Several factors contribute to this:

- **Misunderstanding of hospice coverage:** The National Hospice Foundation reported that, as late as 2006, 75% of Americans did not know that hospice care can be provided in the home and 90% did not realize that hospice care is covered through Medicare.  

- **Underutilization:** Hospice care is commonly accessed very late in disease progression making it less effective than it could be. In the United States, the average length of hospice care is less than 60 days, and the median length of care is only 20.6 days, with 30% of those who elect hospice care dying within 7 days or less.  

- **Requirement to forgo life-prolonging therapies:** Medicare does not pay for life-prolonging care related to a terminal illness, though it will pay for medications to treat health problems, such as diabetes or high blood pressure. However, this “all or none” protocol that hospice requires is considered by some to be too restrictive and may be a key reason patients are less likely to pursue hospice care.  

**Coverage of Palliative and Hospice Care**

The Medicare Hospice Benefit dominates the accepted wisdom about palliative care; however, the rigidity of the benefit is considered by some to be a barrier to expansion of innovations to the Medicare population. The Medicare hospice benefit is available to Medicare beneficiaries under the following conditions:

- They are eligible for Medicare Part A.
- They have a doctor and hospice medical director certifying that they are terminally ill and have 6 months or less to live, if their illness runs its normal course.
- They sign a statement choosing hospice care instead of other Medicare-covered benefits to treat their terminal illness.
- They get care from a Medicare-certified hospice program.

> “Acceptance of one’s mortality is a process, not an epiphany. You need help with this process and one source is hospice. The problem with the Medicare hospice benefit is that you cannot access this help until you have already gone through the process all by yourself.” — Dr. Randall Krakauer

There are, however, clear benefits to providing palliative care outside of the Medicare hospice benefit. Some patients with serious illnesses may have more than 6 months to live if their illness runs its normal course. Patients who may die within 1 year due to a serious illness can benefit from palliative care. Some private health plans are expanding access to palliative care and/or offering a liberalized hospice benefit. The National Business Group on Health (NBGH) recommends that benefit plans should include hospice coverage for individuals with an estimated life expectancy of 12 months or less.

Medicare and most commercial health plans will cover palliative care consultations by a physician or a nurse practitioner and...
may also reimburse for the services of licensed clinical social workers. The reimbursement mechanism essentially mirrors that of any specialty consultation. However, for other members of the palliative team (eg, nurse or spiritual care provider), few health plans offer reimbursement. The costs of these other professional services are paid for by the hospital or the physician practice that employs the palliative care team members. NBGH recommends that benefit plans include access to a wide range of cancer care providers, including palliative care specialists.

Medicare Care Choices Model

The Affordable Care Act of 2010 authorized establishment of a 3-year Medicare Hospice Concurrent Care demonstration project, which would allow hospice-eligible patients to receive other Medicare-covered services while receiving hospice care. On March 18, 2014, CMS announced the launch of an initiative called the Medicare Care Choices Model to develop innovative payment systems to improve care options for beneficiaries by allowing greater beneficiary access to comfort and rehabilitative care in Medicare and Medicaid. This program will test improvements to certain Medicare beneficiaries’ quality of life while they are receiving both curative and palliative care.

The Medicare Care Choices Model provides a new option for Medicare beneficiaries with advanced cancers, chronic obstructive pulmonary disease, congestive heart failure, and HIV/AIDS. They must meet hospice eligibility requirements under the Medicare hospice benefit to receive palliative care services from certain hospice providers while concurrently receiving services provided by their curative care providers.

Several interviewees expressed the opinion that although the Medicare Care Choices demonstration is a step forward, greater progress is needed to support better care and reimbursement for patients with advanced illness upstream from hospice eligibility.

Summary

As the nation ages, more will be demanded of the health care system to address the needs of patients with advanced illnesses, such as cancer, where age is a strong risk factor. Functional and cognitive impairment, comorbidities, increased side effects of treatment, and the need for social support are among the issues often seen in older adults with cancer, which can complicate their care. Early palliative care and ACP are integral to identifying and meeting the distinct goals of cancer care, particularly in older adults. Compelling data demonstrate that patients who receive palliative care along with cancer treatments tend to enjoy better quality of life and live longer, even while shared decision making among such patients has the potential also to reduce costs.

As reported, palliative programs are on the rise and leading initiatives, such as those featured in this report, promote understanding of the benefits of shared decision making and exemplify how care delivery can be successfully redesigned to integrate ACP.

“Over the last decade, Aetna, as well as others, have demonstrated that we can move the needle to a considerable extent, and public and professional perceptions have changed. Advanced illness programs are growing rapidly now among health plans and nearly all large hospitals have palliative care programs. But in all honesty, I would say we have much more distance left to travel than distance already traveled here.”

—Dr. Randall Krakauer

Meeting the IOM’s goals for high-quality, accessible, and affordable cancer care calls for continued efforts to develop tools to support communications between health care providers and patients, as well as patients and their families. Care retooling, technology, and payment reform can enable the process of person-centric decision making across the care continuum.

“My simple goal is that every patient and family say when they reach the end of life, “we made all the right decisions for the right reasons, at the right time. We have no regrets about any decision we made.””

—Dr. Bud Hammes

“The most important lesson learned [from our OMH initiative] is that practices can transform but the durability of that transformation is really dependent on alignment across all payers.”

—Dr. John Fox

“I think we are reawakening some of the deepest commitments we make as healers to others as human beings. We are providing real health care, not just treatment of illness. I hope we continue to work together to discover new and better ways of caring for each other because it is the highest human endeavor we have.”

—Dr. Brad Stuart
Appendix

The key stakeholders interviewed for this report identified a number of resources that may be of help to other organizations in implementing programs supporting palliative care and ACP.

Palliative Care Screening Tools

Several interviewees mentioned tools their programs use in screening patients for palliative care needs.

Memorial Symptom Assessment Scale (MSAS): Lists 24 symptoms and asks patients with cancer how often they had the symptom in the last week, how severe it usually was, and how much they were distressed or bothered by it (see http://www.npcrc.org/files/news/memorial_symptom_assessment_scale.pdf)

Memorial Symptom Assessment Scale – Short Form: An abbreviated version of the MSAS that only measures level of distress from selected symptoms (see http://www.npcrc.org/files/news/memorial_symptom_assessment_scale_short.pdf)

CancerSupportSourceSM Distress Screening Program: The first comprehensive distress screening program developed for community-based hospitals, physician practices, and advocacy organizations to integrate screening, referral, and follow-up care through a single, streamlined, Web-based program. It enables providers to link patient-reported needs with in-house and community support services (for more information, go to http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/CancerSupportSource-2/Screening-Referral-Program.html)

Palliative Performance Scale: A tool that correlates well with actual and median survival time for cancer patients and can be useful in identifying and tracking potential care needs of palliative care patients, particularly as their needs change with disease progression (see http://www.healthcare.uiowa.edu/igec/tools/function/palliativePerformance.pdf)

Resources Promoting Conversations Between Providers and Patients

Advance Care Planning Decisions: A nonprofit foundation whose goal is to empower patients and families with knowledge has produced more than a dozen videos that illustrate the medical conditions patients have, including advanced cancer, and the treatment options they face. These video support tools are available for showing in a clinical setting and are designed to help patients partner with their clinicians to plan for future medical care (see http://www.acpdecisions.org/videos/).

Choosing Wisely® Campaign (www.choosingwisely.org): A national effort led by the American Board of Internal Medicine Foundation to help physicians, patients, and other health care stakeholders consider the overuse of health care resources. It aims to promote conversations between physicians and patients by helping patients choose care that is:
- Supported by evidence
- Not duplicative of other tests or procedures already received
- Free from harm
- Truly necessary

Fifty-seven national health care provider organizations representing more than 1 million providers have developed lists of Five Things Physicians and Providers Should Question in recognition of the importance of conversations to improve care and eliminate unnecessary tests and procedures.

Advanced Illness Checklist®: Dr. Susan Block, a co-director of the Harvard Medical School Center for Palliative Care, proposed this checklist for discussing values and goals about end-of-life care, which is currently the basis of ongoing research.
- **Prognosis** – What is your understanding of where you are and what the future may hold with your illness?
- **Information** – How much information do you want from me about what is likely to be ahead with your illness?
- **Fears/worries** – What are your biggest fears and worries about the future with your illness?
- **Goals** – If your health situation continues to get worse, what are your most important goals?
- **Tradeoffs** – If you become sicker, how much are you willing to go through, in terms of procedures, machines, and being in the hospital, in order to have the possibility of gaining more time?
- **Function** – Are there specific health states that you would find unacceptable? For example, being on machines, in a coma, or unable to care for yourself?
- **Family** – How much have you discussed your goals and wishes with your family?

Palliative Care and the Human Connection: Ten Steps for What to Say and Do: This video resource features Diane Meier, Director of the Center to Advance Palliative Care. In this video, health care professionals are presented with 10 critical steps to follow when having difficult conversations, such as with someone whose incurable cancer has progressed (see http://www.jhartfound.org/blog/tools-you-can-use-ten-step-for-communicating-with-patients-about-serious-illness-from-the-center-to-advance-palliative-care-video/).
Resources for Patients

Advance Care Planning Coalitions: Many US communities have advance care planning coalitions, which are collaborative efforts that offer resources to encourage families and communities to have discussions regarding end-of-life care choices and to provide guidance, direction, or support. Listed are several examples of coalitions and their Web sites:

- Honoring Choices® Minnesota – www.honoringchoices.org
- Making Choices Michigan – makingchoicesmichigan.org
- Chicago End-of-Life Care Coalition – www.cecc.info

Five Wishes®: An easy-to-use legal document that lets patients plan in advance for how they want to be cared for in case of a serious illness (see www.agingwithdignity.org/five-wishes.php for more information). The document allows patients to designate the following:70:

- Wish One – a caretaker who will make decisions on the patient’s behalf
- Wish Two – a living will, which puts in writing the kind of medical treatment patients want or don’t want if they become seriously ill and can’t communicate to anyone
- Wishes Three and Four – clear directions on how patients want to be treated during an illness so their dignity is maintained
- Wish Five – the opportunity to tell others how patients want to be remembered and to express other things important to them

Resources for Employers

The National Business Group on Health (NBGH) has created several resources related to cancer management for employers.

An Employer’s Guide to Cancer Treatment and Prevention is the result of collaboration between NBGH and NCCN. This toolkit is a comprehensive set of practical and usable resources to help employers offer evidence-based cancer care to employees and their dependents. Several recommendations apply to benefits regarding coverage for palliative and hospice care.65

Pathways to Managing Cancer in the Workplace is a guide that provides employers with practical ways to support employees who have cancer, as well as their caregivers.71

Impact of Advanced Illness on the Workplace: What Employers Need to Know is a toolkit that provides information on palliative and end-of-life care. Components include the impact on the workplace of employees as caregivers, advance health care directives, and engaging your workplace in advanced illness planning.72

Improving the Quality of Palliative Care Programs

There are several initiatives under way to standardize care and track, measure, and evaluate palliative care programs.

Palliative Care Guidelines: Two organizations have created guidelines that apply to palliative care:

- Clinical Practice Guidelines for Quality Palliative Care, published by the National Consensus Project for Quality Palliative Care73
- Palliative Care Clinical Practice Guidelines in Oncology™ published by NCCN®

National Palliative Care Registry™ (The Registry): This is the only data repository of its kind and was launched by the Center to Advance Palliative Care to track hospital palliative care services and standardize structures and processes in this field. The Registry is collecting data based on data year 2012 and will be publishing reports based on those findings.74

National Voluntary Consensus Standards: Palliative Care and End-of-Life Care: This resource reports on an evaluation of 22 palliative care and end-of-life care measures considered under the National Quality Forum’s Consensus Development Process. Fourteen measures were recommended for endorsement and address pain and dyspnea management, care preference, and quality of care at the end of life.75

Measure Applications Partnership (MAP): This public-private, multistakeholder group was convened by the National Quality Forum in 2011 to provide guidance on public reporting measures and performance-based measures and payments that can be applied to hospice and palliative care providers. In 2012 MAP identified a “core set” of specific quality measures and noted significant areas where no or few measures exist, signaling opportunities for the measure development community to step in to fill important gaps.75

American Society of Clinical Oncology (ASCO) Virtual Learning Collaborative (VLC) Pilot: This joint initiative between ASCO and the American Academy of Hospice and Palliative Care Medicine is funded by the Agency for Health Care Research and Quality and the California HealthCare Foundation. The project goal is to assess the feasibility of a quality improvement learning collaborative that is virtual and relies on a technology-based infrastructure. Teams participating in the pilot are working to improve the quality of palliative care delivered in oncology (see http://www.asco.org/quality-guidelines/asco-virtual-learning-collaborative).

Palliative Care in Oncology Symposium: This inaugural educational opportunity for oncology professionals, offered by ASCO and to be held October 24-25, 2014, will feature sessions about how to integrate palliative care skills into cancer care across the trajectory of the illness (see http://pallonc.org/).
References


Issues in Focus:
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