The Affordable Care Act and End of Life Care:
A Voice for the Dying

Introduction

It is estimated that more than 1,500 people will die from cancer each day in 2011, which will result in approximately 570,000 lives lost for the year.¹ With one in four people dying as a result of this disease, there is a need to demand better and more efficient use and coverage for end of life care. The goal to maintain the best quality of life should be one for every patient diagnosed with cancer. Research shows, however, that people with a terminal diagnosis often either do not receive palliative care or hospice or, if offered, it is too late in the course of the disease to make an impact.²

The Institute of Medicine in its report Palliative Care for Cancer notes that half of people dying of cancer suffer from a number of symptoms including pain, labored breathing, distress, nausea, confusion and other physical or psychological conditions that go untreated or undertreated and vastly diminish the quality of their remaining days.³ Unfortunately, cancer is a disease that also affects the family and caregivers of patients, and the impact of this suffering during the dying process is reported to have an immense emotional and financial burden on them.⁴

Cancer also has a burdensome effect on our health care system. With the overwhelming majority of cancer patients over the age of 55, the cost of care poses the greatest impact to the Medicare payer system. This program pays for the health care services provided to approximately 80 percent of all individuals who die in the United States.⁵ It is well documented that Medicare expenditures increase substantially during the last year of life. Reports indicate that about a quarter of the total Medicare budget is spent on services to beneficiaries during a patient’s last year of life, and an astounding 40% of it within the last 30 days.⁶

The Utilization of Palliative Care and Hospice

For patients with a poor prognosis due to advanced cancer, death is a likely outcome. When a cure is not possible, it is important for providers to know the preferences of patients and families for where and how they want to be cared for during the last few months of life. The words “hospice” or “palliative care” may never be uttered by the oncology team, which for the patient and family could mean the difference between a focus on quantity of life rather than quality.⁷ There is a distinction between these services and it is an important one for patients, families, clinicians, policy makers and payers.

Palliative care for cancer is defined by the World Health Organization (WHO), and adopted by the National Cancer Policy Board (NCPB), as “active total care of patients whose disease is not responsive to curative treatment.”⁸ These two organizations also support the notion that aspects of palliative care should be offered at the beginning of a cancer diagnosis, with increased intensity and services as the disease progresses.⁹
There are six skill sets that encompass palliative care: communication, decision making, management of complications of treatment and the disease, symptom control, psychological care of the patient and family, and care of the dying. Studies have shown that palliative care services can have a meaningful effect on a cancer patient’s quality of life and end of life care provided it is offered early in the course of the disease.

In a recent study of advanced lung cancer patients, integration of palliative care with oncologic services resulted in survival that was prolonged by approximately two months and clinically meaningful improvements in the patients’ quality of life and mood. Equally as important, the use of palliative care resulted in greater documentation of resuscitation preferences and less aggressive care at the end of life. The less aggressive care included reduced chemotherapy and longer hospice care. While this study was limited to advanced lung cancer patients, the results show promise for improved patient quality of life and mitigation of unnecessary and burdensome personal and societal costs.

Sadly, there is an issue in this country in that palliative care services are often delivered late in the course of treatment, which is a missed opportunity for improved quality of care and a reduction in the use of medical services. There are several reasons attributed to this gap in services for the dying. First, communication between clinicians and patients about the fact that their cancer may be incurable begins too late. While it is certainly hard for clinicians to predict death, there is definitely an issue with physicians deciding how and when a terminal prognosis should be communicated. Couple the communication issue with a lack of adequate reimbursement for office visits to discuss advanced care planning, and the patient and family are operating at a deficit as they try to plan for how aggressively to treat the disease.

While research supports introducing palliative care earlier upon diagnosis of advanced cancer, these services are the bedrock of hospice care. The Medicare Hospice Benefit, established in 1982, is available to beneficiaries in the last six months of life. Physicians must certify that a patient is terminally ill and has six months or less to live. The hospice care period is two 90-day periods followed by an unlimited number of 60-day periods. At the start of each period of care, the hospice director must certify that the patient is terminally ill. Hospice services covered under this benefit include both home and inpatient care. Over the years, hospice utilization has certainly increased. Approximately 1.56 million individuals took part in hospice care in 2009, which was up from 1.2 million just four years earlier. Despite these large numbers, though, hospice remains underutilized for advanced cancer patients.

Given the geographic availability of services and varied estimates of utilization, “20%-50% of the otherwise eligible cancer patient population dies each year while receiving formal hospice care.” Medicare data shows that the median survival for cancer patients in hospice is two to three weeks, and many of these patients die within days of referral. Sadly, patients are often dying in between the referral and provision of services. Given these relatively short time
frames, there appears to be significant underutilization in regard to the actual timing of the referral.26

The Medicare Hospice benefit affords beneficiaries a per diem coverage for services, ranging from $100 to $120 per day, depending on the region in the country.27 Most hospice patients are cared for at home, however, patients also receive services at inpatient hospices and nursing homes. The goals of care include comfort and quality of life, minimization of future hospitalizations and the avoidance of expensive and aggressive care. If the choice was dying at home or dying in a hospital, most patients with a serious illness prefer to be at home at the end of life.28

There are the patients, however, that want life-sustaining care, even when the reality of a cure or remission has vanished. When clinicians do not have an honest conversation with patients about their prognosis and the full range of care options, including early palliative care, many patients “acquiesce to more aggressive care without fully understanding its impact on the length and quality of life.”29 Such aggressive treatment not only emotionally and financially impacts the patient and family, but the health care system also suffers a great financial burden. It is estimated that the costs of dying from cancer are 20% higher than average costs for other forms of death.30 With one quarter of Medicare dollars spent in the last year of life, and half of that spent in the last month of life,31 it is critical with a rapidly aging baby boomer population, that end of life care become a part of our national health care discussion.

The Affordable Care Act and End of Life Care

The Affordable Care Act of 2010 addresses some aspects of end of life care; however, it falls short in making services for the dying a priority. Palliative care for the chronically ill is not a universally reimbursable expense. It is often a service that hospitals provide to patients, and the service is deemed valuable and sustainable because of the overall cost savings in health care expense to the institution. While palliative care is the type of care that is offered in hospice, there is growing practice of using palliative care to help patients with chronic illness, of which cancer is one. There are currently no universal standards and widely accepted protocols for palliative care in both hospitals and nursing homes.32 While health reform did not specifically address palliative care as a distinct service from hospice care, there is a need to have Federal agencies develop a research agenda on palliative care to address issues such as the development of practice guidelines and methods of quality improvement, as well as the exploration of reimbursement options.33 There is not only a cost savings associated with chronic illness and palliative care, but also, and more importantly, the improved quality of life for the patient that will be a direct result of this prioritization, a point which is often left out of many policy discussions.
While there certainly needs to be a shift in physician education and practice around making recommendations for end of life services, there are still relevant provisions of the Affordable Care Act that may have an impact on cancer patients and hospice care.

**Accountable Care Organizations and Cancer**

In an attempt to streamline health costs and create effective performance measurement standards, emphasis has been placed on Accountable Care Organizations (ACOs). Under the Affordable Care Act, ACOs were created as a new payment model for Medicare. The general premise behind ACOs is coordinated care, improved quality and fewer healthcare costs. For cancer patients, there are many specialists involved in treatment, including oncologists, radiologists, surgeons, nurses and nurse practitioners, social workers, primary care physicians, and palliative care teams. However, it may depend on the clinical setting whether the services offered are coordinated on every level and whether they are comprehensive in nature. Since palliative care and hospice are underutilized with oncology patients, there may be an opportunity for these services to have a more prominent role in ACOs.

While coordinating care and quality measures are not new concepts, the oncology field has in fact been working on the improvement of measuring value and quality of care through voluntary reporting on 89 measures of quality. These efforts can certainly inform the creation of ACOs around cancer care, which according to health reform, can take on many forms. Whether a group of providers and suppliers commit to work together, providers in group practices work together or individual practitioners partner with hospitals, an eligible ACO must have 5000 patients assigned to it for at least three years. During this time period, the ACO will be responsible for cost, quality and the overall care of Medicare patients. Experts have agreed that among other measures, guaranteeing compassionate and appropriate end-of-life care are areas for performance improvement in the ACO. With coordinated care and provider incentive towards more efficient care, it is possible that through ACOs cancer patients facing the end of their life may experience more referrals for palliative care and hospice, as both services have been shown to reduce costs and lengthy hospitalizations.

Implementing ACOs will not be without challenges as there will be a shift in payment models and operational changes in historical oncology practices; however, if there are opportunities to test ACOs and their impact on cancer patients across the continuum of care, it may prove to save money, improve performance, and most importantly, improve quality of life for terminal cancer patients.

**Hospice Demonstration Project**

While the hospice benefit was established nearly thirty years ago, access to care is still restricted by the requirements that the patients have less than six months to live and that when receiving hospice care, they must forgo all life-sustaining treatment. For cancer patients, the decision to stop receiving chemotherapy is a very difficult one, as it is symbolic of defeat and imminent
death. There is a psychological barrier for patients to keep fighting until the end, as there may be a chance that treatment will keep the cancer at bay and buy them more time. And with an admission to hospice, the time is running out and there is no more hope.

The Affordable Care Act created a hospice concurrent care demonstration project. This is a three year project, and one of the most important components of this program for cancer patients is that they will be allowed to receive aggressive treatment as well as hospice care. By changing this fundamental component of hospice coverage, it is likely that the eligibility requirement of a prognosis of six months of left to live will be less strict.

One of the major goals of this project will be to measure the effects of concurrent care on costs to Medicare. Given the typical high rate of hospitalizations during the last weeks of a cancer patient’s life, it will be important to reveal whether additional treatment costs will be “offset by reduced acute care utilization with usual care.” It will be critical for the evaluation to compare the costs of additional treatment, the usual care, and typical hospice use in order to determine cost effectiveness. However, this project needs to also focus on more than just cost savings to Medicare. There has to be a priority placed on measuring the enrolled patients’ quality of life.

Quality of care should be a priority for measuring the success of the demonstration project. It will be important to note if concurrent care affected associated symptoms and in fact improved the quality of life. It will be critical to engage families in this evaluation, as cancer patients often engage family members in the decisions about discontinuing life sustaining measures and other treatment options.

Cancer patients and their families face challenges with access to hospice services, and this is an even greater issue with ethnic minorities and those facing health disparities. It will be critical for the demonstration projects to determine whether the concurrent care options and less strict eligibility criteria promote utilization earlier in the final months of terminal patients.

Lastly, the hospice concurrent care demonstration project should evaluate the effect on patients’ survival. Studies have shown that palliative care has in fact increased survival on terminal cancer patients; therefore, it will be important to determine whether aggressive treatment at the end of life coupled with hospice care extends life expectancy.

This three year demonstration project affords Medicare the opportunity to gather data on cost savings, access to services, quality of life, and survival. It is imperative that the quality of life evaluation play a key role in determining the success of this project, because while cost savings is certainly important, terminal cancer patients suffer greatly and often needlessly towards the end of their lives.
Medicare reimbursements for discussions

One area that may have greatly benefited terminal cancer patients was left out of the ACA. Not included in the bill was the decision to reimburse physicians for the time spent discussing end of life options and the course of the disease with patients. Studies have shown that such conversations between patients, families and physicians have lead to improved quality and length of life. Every patient should expect an open and honest dialogue with his or her physician, even when the news is difficult for all. While the oncology field may need a culture shift in forgoing aggressive treatment until death, this is a change that will take time. However, one change that can occur more rapidly is to allow end of life conversations to be a reimbursable expense. Every terminal cancer patient deserves to die with dignity, and given the choice of all options, including palliative care, continued aggressive treatment, and even hospice, patients and their families should be able to have one final voice against the disease that silences so many.

Conclusion

The Affordable Care Act did not explicitly address palliative care, but it did make some potential improvements to hospice services. There are opportunities in payment reforms and quality improvement initiatives that will hopefully have a positive impact on cancer patients, both terminal and those who will become survivors. It is imperative that cancer be addressed and not avoided in some of the bundling payment and ACO pilot programs, no matter how operationally challenging including cancer may be given the nature of the disease. With a rapidly aging population that faces more chronic diseases than any previous generations, cancer cannot be ignored because the disease will continue to claim lives and also leave thousands of survivors every year to deal with its latent effects and potential reoccurrences.

4 Id at 2.
5 Smits, H.L., Furletti, M., Vladeck, B.C., Palliative Care: An Opportunity for Medicare. New York: Institute for Medical Practice Mt. Sinai School of Medicine, 1.
6 Financing end of life care in the USA
8 IOM Summary.
9 Id.
10 Id.
13 *Id.*
15 *Id.*
17 Smits, H.L., Furletti, M., Vladeck, B.C. at 3.
20 Rethinking Hospice Eligibility 1031.
21 *Id.*
22 Daugherty, C.K. at 124.
23 *Id.*
24 *Id.*
25 *Id.*
26 *Id.*
27 Daugherty, C.K. at 129.
28 Goodman, D.C., Fisher, E.S., Chang, C. et al., at 3.
29 *Id.*
30 IOM at 2.
31 *Id.*
32 Smits, H.L., Furletti, M., Vladeck, B.C. at 10.
33 *Id.*
36 Bailes, J.S., Kamin, D.Y., Foster, S.E. at 589.
37 *Id.*
38 Fisher, E., Shortell, S.M. at 1715.
40 *Id.*
41 *Id.*
42 Casarett, D.J. at 1031-32.
43 Casarett, D.J. at 1032.
44 *Id.*
45 *Id.*
46 *Id.*
47 Bailes, J.S., Kamin, D.Y., Foster, S.E. at 591.
48 *Id.*