The Affordable Care Act and End of Life Care:
Executive Summary

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.[i] 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.[ii]

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.[iii] 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.[iv]

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.[v] 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.[vi]

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.[vii] 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.[viii] 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.

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.

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[i] American Cancer Society. (2011). *Cancer Fact & Figures 2011.* Atlanta: American Cancer Society.
[ii] Temel, J. S., Greer, J.A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V.A., … Lynch, T.J. (2010). Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *N Engl J Med 363; 8, 733.*
[iii] Institute Of Medicine. *Improving Palliative Care for Cancer Summary and Recommendations*. Washington, DC: Institute of Medicine and Commission on Life Sciences National Research Council, 2.
[iv] *Id at 2*.
[v] 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.
[vi] Financing end of life care in the USA
[vii] Smits, H.L., Furletti, M., Vladeck, B.C. at 10.
[vii] *Id.*