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The Affordable Care Act and End-of-Life Care for Patients with Cancer

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The Affordable Care Act (ACA) expanded access to high-quality end-of-life care for Americans with serious illness, including cancer. Before the ACA was enacted in 2010, nearly 715,000 patients died in hospitals annually,¹ despite evidence that most Americans prefer to die at home.² Moreover, fewer than half of Medicare beneficiaries used hospice before death, despite evidence that hospice services improve cancer patients' quality of life near death and caregivers' bereavement outcomes.^{3–6} ACA-stipulated programs and subsequent efforts were designed to address these deficiencies in access to high-quality end-of-life care. However, important gaps in coverage persist. In this article we highlight the impact of the ACA on end-of-life care for individuals with and without cancer.

ACA Impact on End-of-Life Care

ACA provisions addressed three specific domains of end-of-life care: 1) Expansion of concurrent hospice and oncologic care, 2) Payment reform at the end of life, and 3) Quality improvement (Table 1).

Concurrent Hospice and Oncologic Care

Evidence Basis—Several prospective randomized clinical trials have demonstrated that integrating specialty palliative care with standard oncology care in adults leads to significant improvements in quality of life and care without a survival decrement.^{7–10} Additionally, the improved outcomes associated with early, concurrent palliative care likely lead to reduced health care spending and utilization in both inpatient and outpatient settings.^{10–13} In response to these data, the American Society of Clinical Oncology (ASCO) released a clinical practice guideline recommending the provision of early, concurrent palliative care for all patients with advanced cancers.^{14,15}

Hospice is one of the largest providers of palliative care in the United States. However, one of largest barriers to hospice enrollment is that patients are often forced to choose between receiving hospice or disease-modifying treatments (e.g. chemotherapy).^{16,17} Some limited pilot programs, which have tested the provision of concurrent hospice and disease-

modifying therapies have documented increased hospice length-of-stays, decreased utilization of hospital-based care, and stable to decreased costs.^{18–20} Despite this, the reality is that few patients currently have access to concurrent hospice and oncologic care.

The prospect of forgoing potentially life-extending treatment to enroll in hospice is particularly distressing for parents of children with serious illness.²¹ While the need for palliative care in this patient population is well documented, prospective evidence supporting concurrent pediatric palliative and oncologic care for children with poor prognoses is lacking.^{22–24} However, results from several studies suggest that early palliative care consultations improve the detection of untreated symptoms, enhance communication and documentation of advance care planning, and increase the likelihood of hospice enrollment and avoidance of in-hospital deaths.^{25–29}

In 2000, the American Academy of Pediatrics issued a report recommending implementation of an integrated palliative care approach for children with life-limiting illness.³⁰ In 2003, the Institute of Medicine report *When Children Die* recommended that both public and private insurance plans reimburse health care providers for providing comprehensive palliative care.³¹ Despite these recommendations, coverage of concurrent disease-modifying therapy and hospice was limited prior to passage of the ACA.

Policy Provisions—Section 2302 of the ACA requires that programs for children enrolled in state Medicaid or Children’s Health Insurance Programs (CHIP) must allow patients to receive hospice care with disease-modifying treatment.³² The federal provision applies to children who are: 1) less than 21 years of age, 2) terminally ill (defined as having a prognosis of less than 6 months to live), and 3) eligible for the state’s Medicaid or CHIP programs. The concurrent care waiver has the potential to have a significant positive impact on the quality of end-of-life care for children with life-limiting illnesses. Most of the palliative care provided under the ACA is delivered in hospice and community settings.³³

Additionally, while concurrent hospice care for adults was not stipulated in the ACA legislation, several demonstration programs stemming from ACA-funded institutes have expanded the evidence base for concurrent palliative care. Perhaps the most significant was the Medicare Care Choices Model, established through the Centers for Medicare and Medicaid Services Innovation Center (CMMI).³⁴ The Medicare Care Choices Model (MCCM) was the first CMS model to offer “open-access hospice,” allowing patients with a life-expectancy of less than six months to receive concurrent disease-modifying therapies and hospice services.³⁵ There are 141 hospices currently participating in the model—half of which were randomly assigned to start offering “open-access hospice” in 2016, and half of which will start in 2018. While results from this evaluation are forthcoming, the MCCM will provide the largest prospective evaluation of providing concurrent hospice and disease-modifying therapies.

Payment Reform at the End of Life

Evidence Basis—The increasing cost of cancer care has made payment reform in oncology a national policy priority, particularly at the end of life. The National Cancer Institute estimates that the cost of cancer care will exceed \$174 billion in 2020 due to

growing numbers of cancer survivors and the aging US population.³⁶ In 2009, ASCO released a statement calling, in part, for research into payment reform and alternative payment models.³⁷ A recent systematic review suggests that facilitated advance care planning reduces costs of care at the end of life for inpatients by up to \$65,000 per patient.³⁸ However, there are few prospective evaluations of alternative payment mechanisms in end-of-life cancer care.

Policy Provisions—The ACA mandated hospice service payment reform with the goal of reducing barriers to access to high-quality hospice care.³⁹ It also called for the testing of value-based purchasing for hospice. In response, CMS implemented two different per diem payment rates for hospice services, which lowered reimbursement rates for patients enrolled in hospice for more than 60 days and curbed incentives for long-stay hospice patients.⁴⁰(p1)

Through CMMI, the ACA has also spurred investigations of novel payment mechanisms for end-of-life and cancer care. Based on previous models of coordinated oncology care, CMMI devised the Oncology Care Model (OCM), which provides a fixed Monthly Enhanced Oncology Services (MEOS) payment for participating practices to assist in coordinating care for oncology patients.⁴¹ While the OCM is explicitly for Medicare beneficiaries currently receiving chemotherapy, all patients must have a care management plan that includes information about prognosis, treatment goals and expected response to treatment, and advance care plans, including advanced directives and other legal documents.^{41,42} Moreover, key OCM quality measures include hospice admissions at least 3 days before death and patient experiences with care. Many have argued that similar performance-based and bundled payments specifically for end-of-life care could improve value.^{39,43} Similarly, the ACA included integration and participation of palliative care and hospice programs in demonstrations of other delivery and payment models, such as accountable care organizations (ACOs) and patient-centered medical homes (PCMHs).⁴³

Quality Improvement in End-of-Life Care

Evidence Basis—Several studies have shown significant variation in quality of care provided by different hospice and end-of-life care providers.^{44,45} Hospice visits in the last days of life vary substantially by race, hospice program, and geographic region of the country.⁴⁶

Policy Provisions—The Hospice Quality Reporting Program (HQRP) was mandated by the ACA, ensuring public reporting of hospice quality data. Under this provision, the failure to submit quality data results in a 2% reduction in hospice reimbursements for the following year.⁴⁷ Such reporting shines a spotlight on many important aspects of hospice care, including the patient experience of care and length of hospice stays. However, there are no explicit payment incentives tied to achieving quality metrics, only for the reporting of metrics.

Potential Gaps in ACA Coverage of End-of-Life Care in Cancer

While there are several provisions within the ACA that have a positive impact on end-of-life care for patients with cancer, multiple gaps remain in the ACA's specific legislation. First,

ACA provisions around meaningful use do not require robust documentation of advance care planning,⁴⁸ or provide reimbursement to clinicians for these services. This is particularly important for patients with cancer at the end of life, including minorities who have low rates of early advance care planning documentation.^{49–52}

The ACA's hospice provisions also include Section 3401(g), which mandates a productivity adjustment factor designed to reduce hospice reimbursement rates for the reported purpose of ensuring Medicare sustainability. However, hospice costs represent a very small proportion of overall spending for patients with cancer, and are dwarfed by inpatient expenditures.⁵³ Additionally, Section 3132 of the ACA mandates that patients enrolled in hospice for more than six months must have a face-to-face visit with a physician or nurse practitioner to confirm that they still meet hospice enrollment criteria, in light of concerns about overall costs, fraud, and abuse among for-profit hospices; hospices with high recertification rates are subject to medical review. While protecting against fraud is undoubtedly important, one unintended consequence of this provision is an additional burden imposed on physicians and nurse practitioners, particularly in rural areas, where face-to-face visits come with significant transportation and other costs to hospices.⁵⁴

Implications of ACA Repeal

Risk Sharing and Payment Reform

As President Trump's administration advocates for ACA repeal in favor of shifting responsibility for healthcare funding to the states, health care organizations, clinicians and citizens will be expected to take on more risk. If this occurs, patients and families will likely face narrower health plan networks, while deductibles, co-pays, and insurance costs may rise.⁵⁵ While coverage for preexisting conditions may remain intact, other out-of-pocket costs are likely to increase if the ACA's Medicaid subsidies are replaced with Medicaid block grants to states or individual flat tax credits based upon age.⁵⁶

Delivery Reform

The loss of concurrent palliative care and hospice options for children and adults, either through repeal of the aforementioned Section 2302 and/or repeal of CMMI and its MCCM, could adversely impact seriously-ill individuals with cancer. A shift to a two-payer model, where concurrent care is delivered via a blend of primary commercial and secondary managed Medicaid insurance coverage, may be necessary for children who desire concurrent care, particularly as the CHIP funding expires in 2017.^{21,55} Additional "carve-outs" may also be necessary for patients with life-limiting cancers to receive concurrent disease-modifying chemotherapy and hospice care.

Conclusion

In addition to insurance expansion—that provides key access to care for individuals who were previously uninsured—there are many direct provisions of the ACA that increase insurance coverage and/or access to affordable hospice and concurrent palliative care for patients with cancer. Despite gaps in hospice reimbursement policies and insufficient reach of demonstration projects, a repeal of the ACA will likely increase the costs of end-of-life

care for both patients and payers, while reducing quality. As our health system strives to become more patient-centered, policymakers and providers must consider the implications of ACA repeal and protect those with the most to lose.

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Table 1

Impact of the Affordable Care Act on End of Life Care

Domain	Direct Provisions		Indirect Results of ACA Provisions	
Concurrent Palliative and Hospice Care	Required coverage for concurrent palliative care for children in the Medicaid or CHIP Programs		CMMI demonstration projects testing concurrent hospice care, including the Medicare Care Choices Model	
Payment Reform	1	Revisions to hospice service payment methodology to reduce barriers to access	1	Medicare reimbursement for advance care planning
	2	Calls for value-based purchasing in hospice	2	The Oncology Care Model – testing performance-based episode payments to practices delivering chemotherapy to cancer patients
	3	Potential reimbursement decreases for hospice based on reporting of quality data	3	Inclusion of patients in long-term care and hospice in CMMI demonstration projects
Quality Improvement	1	Hospice Quality Reporting Program (HQRP), ensuring public reporting of hospice quality data	Lack of advance care planning documentation guidelines in meaningful use requirements	
	2	Required face-to-face visit with patients for hospice recertification		