

Improving the Quality of Cancer Care: Implications for Palliative Care

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Abstract

Background and Objective: In September 2013 the Institute of Medicine (IOM) released a report on the quality of cancer care in the United States. We report here on the recommendations of the IOM report and the implications for the palliative care community.

Methods: The IOM report is based on a consensus of literature and expert opinion. The recommendations provide direction for health policy, education, and clinical practice. The report emphasizes the significance of the aging population and implications for cancer care.

Results: The recommendations from the report offer many opportunities for palliative care including enhancing the use of advance care planning and integration of palliative care across the cancer trajectory.

Conclusions: Quality cancer care depends on the integration of quality palliative care. The palliative care community can use this IOM report to guide their collaboration with oncology and to enhance the quality of care provided to cancer patients and their families.

Introduction

A NEW REPORT BY THE INSTITUTE OF MEDICINE (IOM) concludes that cancer care delivery in the United States is in crisis.¹ Demographic changes are greatly increasing the demand for cancer care at a time when the cancer care workforce is shrinking. The rising cost of cancer care is exacting a significant financial toll on patients, their families, and on the nation. Despite these costs, the care that patients receive is often not as patient-centered, accessible, coordinated, or evidence-based as it should be. The cancer care team often neglects the importance of palliative care across the cancer care continuum. And although progress in the understanding of cancer biology is improving cancer treatment, assimilating these advances into practice is challenging given their complexity and the sheer volume of information the cancer care team needs to master in order to provide high-quality cancer care.¹ The tools to improve the quality of care including quality measurement, clinical practice guidelines, and information technology (IT) are not widely used and have serious limitations. Thus, more than a decade after the IOM first addressed the quality of cancer care,² the barriers to achieving excellent care for all cancer patients remain daunting.

Responding to these challenges, the IOM's 2013 report, "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis,"¹ recommends changes to the cancer care delivery system to ensure that patients receive high-quality care. It presents a conceptual framework with six components that guide its recommendations for improving the quality of cancer care (Fig. 1): (1) engaged patients; (2) an adequately staffed, trained, and coordinated workforce; (3) evidence-based cancer care; (4) a learning health care IT system for cancer; (5) translation of evidence into clinical practice, quality measurement, and performance improvement; and (6) accessible, affordable cancer care. Importantly, the IOM concludes that palliative care is a critical component of high-quality cancer care and that it should be delivered across the cancer care continuum.

Importance of the IOM's Report to the Palliative Care Community

The nation is aging, and with increasing incidence, survival, costs, and intensity at the end of life in cancer care the Medicare system will be increasingly stressed.³ Assuming a 2% rate of cancer care inflation in the initial and final years of life, Medicare is projected to spend 39% more on cancer care from

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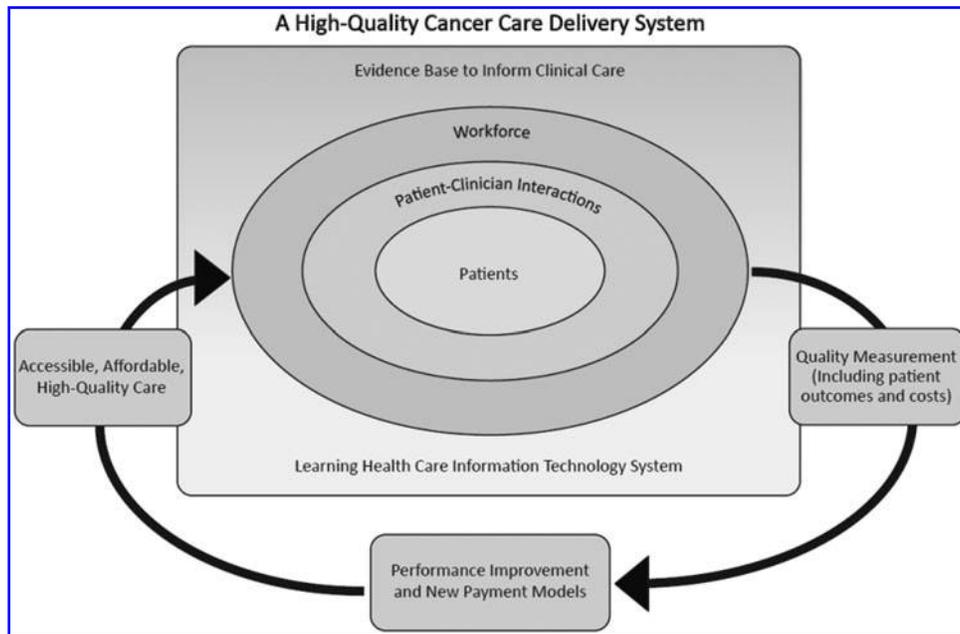


FIG. 1. An illustration of the committee’s framework for a high-quality cancer care delivery system.

2010 to 2020, far exceeding the rate of growth of resources.⁴ In fact, with the burgeoning inflation in cancer drug prices—with prices of more than \$10,000 a month the norm—the growth is likely to be more than 2%. Coupled with a shrinking economic base of workers to support taxes, and a projected shortage of oncology professionals, a “perfect storm” or “silver tsunami” could overwhelm the Medicare system.^{5–6}

The IOM charged a committee with developing a plan for a high-quality, affordable cancer care system. This multidisciplinary group held four meetings to identify pressing problems in cancer care and potential solutions. The report was released September 10, 2013 and is available at the Institute of Medicine website.¹

We summarize here the significance of the IOM’s report for the palliative care community and highlight some specific actions. First, the report recognizes palliative care and hospice care as critical components of high-quality, patient-centered care that will help address health care underuse, misuse, and overuse of interventions. Palliative care and hospice care play a pivotal role in helping to improve care at a cost we can afford.^{7–9} There is increasing evidence that palliative care is the “home run” of American medicine with all four bases covered: (1) a better patient experience with improved communication and less distress; (2) better quality of care with less aggressive end-of-life care and more use of home and hospice care when appropriate; (3) equal or even better survival; and (4) significant cost savings. The benefits of hospice include better symptom management, reduced caregiver distress, honoring patient wishes and communicating these wishes among the members of the care team, equal or better survival, and increased chance of survival of the remaining spouse.^{10–14} The cost savings that average \$2700 per person compared with usual care increase with the amount of time spent in hospice.¹⁵

Second, this report provides actionable information to document the need for additional hospice and palliative care advance practice nurses and physicians.¹⁶ There is opportu-

nity to make change at the national level by working for passage of bills that expand palliative care and hospice care training such as the Palliative Care and Hospice Education and Training Act (H.R.1339),¹⁷ and at the state level with bills such as Maryland House Bill 58 – Hospitals: Establishment of Palliative Care Pilot Programs.¹⁸ The Maryland bill initiates at least five pilot programs, establishes a state baseline by survey of workforce needs, and provides planning for future improvements. There is a need to dramatically increase the number of fellowship and advance practice nurse training positions in palliative care and hospice care, and this will only come with a partnership of state and federal governments and philanthropy.

Third, this report gives us even more impetus to work on new models of care that incorporate palliative care from the time of cancer diagnosis and timely referral to hospice care at the end of life. There are a growing number of reports on how to integrate palliative care and hospice care into specialty care, but there are still too few randomized trials or demonstration projects to establish best practices. Examples of the type of pilot programs we need include health insurance company Aetna Inc.’s Compassionate Care Program,¹⁹ which integrated hospice and palliative care earlier into cancer treatment and found that this integration led to maintained survival and reduced hospitalizations for patients, and saved Aetna 22% in the last 40 days of life.^{20,21} Similarly, efforts by U.S. Oncology²² to better integrate discussions of advance directives, social work counseling, and hospice referrals in patients’ first months of treatment for life-ending cancers has partly contributed to patients experiencing equal or better survival and cost savings of 33% to 35%.^{23,24}

Summary of the IOM’s Recommendations

This section briefly reviews the IOM’s recommendations and discusses the implications for the palliative care

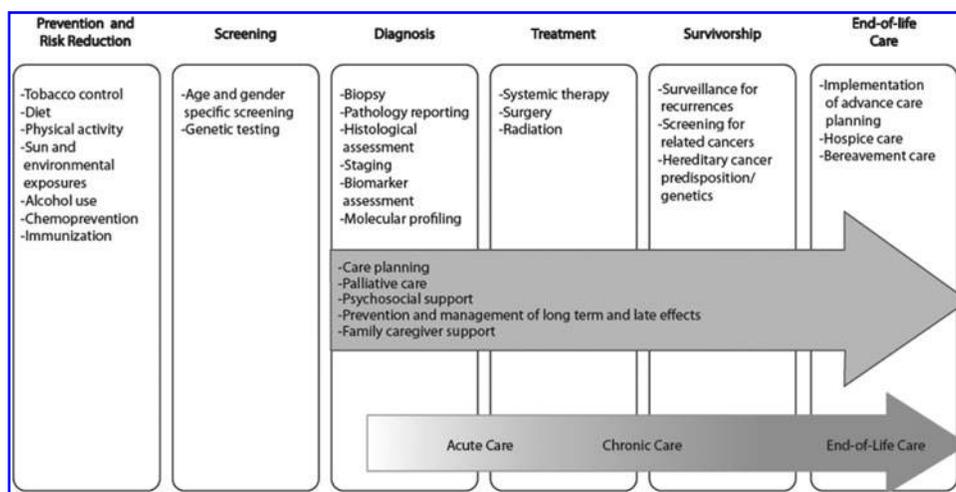


FIG. 2. Domains of the cancer care continuum with examples of activities in each domain. The top arrow identifies components of high-quality cancer care that should span the cancer care continuum from diagnosis through end-of-life care. The bottom arrow identifies three overlapping phases of cancer care, which are a way of conceptualizing the portion of the cancer care continuum that is the focus of this report.

workforce.¹ Figure 2 is a model from the IOM report demonstrating the importance of incorporating palliative care from the time of diagnosis through the end of life in a high-quality cancer care delivery system. The actual IOM recommendations are presented in italic print. Recommendations 1 and 2 are of special importance because they identify a direct role for palliative care in a high-quality cancer care delivery system.

Recommendation 1: Engaged patients

Goal: The cancer care team should provide patients and their families with understandable information on cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and estimates of the total and out-of-pocket costs of cancer care.

To accomplish this:

- *The National Cancer Institute (NCI), CMS, the Patient Centered Outcomes Research Institute (PCORI), as well as patient advocacy organizations, professional organizations, and other public and private stakeholders should improve the development of this information and decision aids and make them available through print, electronic, and social media.*
- *Professional educational programs for members of the cancer care team should provide comprehensive and formal training in communication.*
- *The cancer care team should communicate and personalize this information for their patients at key decision points along the continuum of cancer care, using decision aids when available.*
- *The cancer care team should collaborate with their patients to develop a care plan that reflects their patients' needs, values, and preferences, and considers palliative care needs and psychosocial support across the cancer care continuum.*
- *CMS and other payers should design, implement, and evaluate innovative payment models that incentivize the cancer care team to discuss this information with their*

patients and document their discussions in each patient's care plan.

This recommendation focuses on patient-centered communication, which has been a hallmark of the field of palliative care. Professionals in palliative care have an opportunity to serve as role models for other clinicians in communicating with patients and their families about prognosis, treatment options, palliative care services, psychosocial support, and the cost of care. This recommendation also provides opportunities for palliative care clinicians to advance their communication skills and practices. Communication in palliative care has mainly focused on helping patients to understand their prognosis and establish their goals of care. These conversations have been largely limited to individual conversations between professionals and patients or as part of family conferences. In the future, other aspects of communication should be advanced such as communication with diverse cultures, skills to address existential concerns, and team communication.

In addition, palliative care clinicians could benefit from the improved development and dissemination of decision aids focused on palliative care issues and evaluation of their effectiveness. Video decision aids have been effective in the cancer setting in promoting patients' understanding of end-of-life care options.²⁵⁻³⁰ Decision aids that provide information on prognosis are acceptable and desired among patients with metastatic cancer, and these decision aids could improve patients' knowledge without creating anxiety or diminishing hope. Enhanced training in communication for professionals will also facilitate shared decision making between patients and their clinicians.²⁷

Finally, the health policy implications of possible innovative payment models that incentivize patient-centered communication and shared decision making has long been a need recognized in palliative care. New models of payment for cancer care could potentially increase the number of patients receiving palliative care, thus, increasing the workload of palliative care clinicians.

Recommendation 2: Engaged patients

Goal: In the setting of advanced cancer, the cancer care team should provide patients with end-of-life care consistent with their needs, values, and preferences.

To accomplish this:

- Professional educational programs for members of the cancer care team should provide comprehensive and formal training in end-of-life communication.
- The cancer care team should revisit and implement their patients' advance care plans.
- The cancer care team should place a primary emphasis on providing cancer patients with palliative care, psychosocial support, and timely referral to hospice care for end-of-life care.
- CMS [Centers for Medicare and Medicaid Services] and other payers should design, implement, and evaluate innovative payment models that incentivize the cancer care team to counsel their patients about advance care planning and timely referral to hospice care for end-of-life care.

This recommendation also highlights the critical importance of integrating palliative care into cancer care, including recognizing the role of palliative care across the cancer care continuum as well as timely referral to hospice care at the end of life. With more than 570,000 deaths each year in the United States from cancer, advance care planning and developing consistent methods of ensuring patient access to palliative care from the time of diagnosis and timely referral to hospice at the end of life is critical. The end of life is an area in health care where patients need to be more seamlessly transitioned from disease-focused cancer care to care that emphasizes palliative care, psychosocial support, and the timely referral to hospice care.

Recommendation 3: An adequately staffed, trained, and coordinated workforce

Goal: Members of the cancer care team should coordinate with each other and with primary/geriatrics and specialist care teams to implement patients' care plans and deliver comprehensive, efficient, and patient-centered care.

To accomplish this:

- Federal and state legislative and regulatory bodies should eliminate reimbursement and scope-of-practice barriers to team-based care.
- Academic institutions and professional societies should develop interprofessional education programs to train the workforce in team-based cancer care and promote coordination with primary/geriatrics and specialist care teams.
- Congress should fund the National Workforce Commission, which should take into account the aging population, the increasing incidence of cancer, and the complexity of cancer care, when planning for national workforce needs.

This recommendation provides an opportunity for palliative care clinicians to collaborate with the other members of the cancer care team as well as with primary and geriatric clinicians. Collaboration has traditionally been a focus of palliative care. The expertise of palliative care clinicians in the management of symptoms and quality-of-life concerns in

diseases common in older adults, such as dementia and end-stage cardiac and pulmonary diseases occurring simultaneously with cancer, will make collaboration even more vital in the future of oncology given the aging population.

This recommendation also speaks to opportunities for enhanced interprofessional education. The field of palliative care has much to gain from training specialists in oncology, geriatrics, and palliative care together, and also from training all of the disciplines involved in palliative care together (i.e., nurses, physicians, social workers, etc.). As the demand for palliative care grows, it will be essential that specialist care is provided but that all disciplines are supported in advancing palliative care.

Recommendation 4: an adequately staffed, trained, and coordinated workforce

Goal: All individuals caring for cancer patients should have appropriate core competencies.

To accomplish this:

- Professional organizations that represent clinicians who care for patients with cancer should define cancer core competencies for their membership.
- Cancer care delivery organizations should require that the members of the cancer care team have the necessary competencies to deliver high-quality cancer care, as demonstrated through training, certification, or credentials.
- Organizations responsible for accreditation, certification, and training of nononcology clinicians should promote the development of relevant core competencies across the cancer care continuum.
- The U.S. Department of Health and Human Services (HHS) and other funders should fund demonstration projects to train family caregivers and direct care workers in relevant core competencies related to caring for cancer patients.

This recommendation provides palliative care professionals with an opportunity to educate their oncology colleagues about the provision of palliative care. As the IOM identified, palliative care is an essential element of high-quality cancer care. This education can be integrated into oncology continuing education and include topics such as pain and symptom management, implementation of advance care planning at the end of life, bereavement support, and psychosocial/spiritual care.³¹ The National Consensus Project Clinical Practice Guideline's eight domains can serve as a template for palliative care education for oncology specialists.³² Development of curricula to be used in oncology settings, online resources, train the trainer programs, and other educational approaches could make an important contribution to quality cancer care.

Recommendation 5: Evidence-based cancer care

Goal: Expand the breadth of data collected on cancer interventions for older adults and individuals with multiple comorbid conditions.

To accomplish this:

- The National Cancer Institute (NCI), the Agency for Healthcare Research and Quality, Patient Centered Outcomes Research Institute (PCORI), and other

comparative effectiveness research (CER) funders should require researchers evaluating the role of standard and novel interventions and technologies used in cancer care to include a plan to study a population that mirrors the age distribution and health-risk profile of patients with the disease.

- *Congress should amend patent law to provide patent extensions of up to six months for companies that conduct clinical trials of new cancer treatments in older adults or patients with multiple comorbidities.*

The lack of research in older adults is a major problem for palliative care. Many pharmacologic agents used for pain and other symptoms have not been tested extensively in older adults. In addition, agents used to treat patients' neuropathic pain, agitation, delirium, insomnia, nausea, and other symptoms common at end of life may have serious adverse effects in older adults. The palliative care community should support this recommendation and advocate for more research on older adults, which includes an assessment of symptom management.

Recommendation 6: Evidence-based cancer care

Goal: Expand the depth of data available for assessing interventions.

To accomplish this:

- *NCI should build on ongoing efforts and work with other federal agencies, PCORI, clinical and health services researchers, clinicians, and patients to develop a common set of data elements that captures patient-reported outcomes, relevant patient characteristics, and health behaviors that researchers should collect from randomized clinical trials and observational studies.*

Patient-reported outcomes are critical to improving the quality of palliative care because this discipline has been built on providing care that is consistent with patients' needs, values, and preferences. Thus, it is important that palliative care clinicians be involved in developing the common set of data elements that researchers should collect in randomized clinical trials and observational studies to ensure that these elements include measures that could inform such care. Fortunately, there has been significant work done by palliative care researchers to define key outcomes of interest.^{33,34}

Recommendation 7: A learning health care IT system in cancer care

Goal: Develop an ethically sound learning health care IT system for cancer that enables real-time analysis of data from cancer patients in a variety of care settings.

To accomplish this:

- *Professional organizations should design and implement the digital infrastructure and analytics necessary to enable continuous learning in cancer care.*
- *HHS should support the development and integration of a learning health care IT system for cancer.*
- *CMS and other payers should create incentives for clinicians to participate in this learning health care system for cancer, as it develops.*

The creation of learning health care IT systems for cancer is important to palliative care because it could facilitate the integration of palliative care into oncology care. Knowing how to best treat symptoms, address psychosocial and spiritual needs, provide bereavement support and other aspects of care could provide direction for evolving models of care. This system could provide palliative care clinicians with feedback about how well they are managing patients' pain and other symptoms. In addition, this system could improve the evidence base for palliative care, if the system collects information on the patients' experiences with care.

Recommendation 8: Quality measurement

Goal: Develop a national quality reporting program for cancer care as part of a learning health care system.

To accomplish this, HHS should work with professional societies to:

- *Create and implement a formal long-term strategy for publicly reporting quality measures for cancer care that leverages existing efforts.*
- *Prioritize, fund, and direct the development of meaningful quality measures for cancer care with a focus on outcome measures and with performance targets for use in publicly reporting the performance of institutions, practices, and individual clinicians.*
- *Implement a coordinated, transparent reporting infrastructure that meets the needs of all stakeholders, including patients, and is integrated into a learning health care system.*

The National Consensus Project on Palliative Care has created a foundation for quality measurement across eight essential domains of care.³² These measures have been endorsed by the National Quality Forum, which has created preferred practices as measurable outcomes. The Joint Commission for Accreditation of Health Care Organizations (JCAHO) has also implemented certification in palliative care for hospitals that meet specific quality measures.³⁵ This certification of palliative care programs will help establish quality standards for palliative care programs, which is important in the early development of the palliative care specialty.

Members of the palliative care community can help implement this recommendation by collaborating with their oncology colleagues to incorporate measures of palliative care into the national reporting system for cancer, such as symptom control and care in the final days of life. Palliative care clinicians can also participate in the development of cross-cutting quality measures and in the transparent reporting of these measures.

Recommendation 9: Accessible, affordable cancer care

Goal: Reduce disparities in access to cancer care for vulnerable and underserved populations.

To accomplish this, HHS should:

- *Develop a national strategy that leverages existing efforts by public and private organizations*
- *Support the development of innovative programs.*

- Identify and disseminate effective community interventions.
- Provide ongoing support to successful existing community interventions.

Health care disparities exist in all aspects of oncology care, including palliative care and hospice care. Numerous reports and studies have documented that minority communities often have less access to hospice due to both professional barriers and public misconceptions about the benefits of hospice care.²³ Any efforts to improve access to cancer care services should also address access to palliative care across the cancer care continuum and timely referral to hospice care at the end of life. There remains a need to address professional barriers as well such as reluctance of oncologists to refer patients to palliative care until the final weeks of life.

Recommendation 10: Accessible, affordable cancer care

Goal: Improve the affordability of cancer care by leveraging existing efforts to reform payment and eliminate waste.

To accomplish this:

- Professional societies should identify and publicly disseminate evidence-based information about cancer care practices that are unnecessary or where the harm may outweigh the benefits.
- CMS and other payers should develop payment policies that reflect the evidence-based findings of the professional societies.
- 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.
- If evaluations of specific payment models demonstrate increased quality and affordability, CMS and other payers should rapidly transition from traditional fee-for-service reimbursements to new payment models.

This recommendation is particularly relevant to the palliative care community because it recognizes the enormous issues of waste, futile care, and delayed access to palliative care. New models of payment that incentivize clinicians to align care with their patients' needs, values, and preferences constitute a direct call for improved palliative care because a cornerstone of palliative care is providing care that meets patient's needs, values, and preferences.

Conclusions

This IOM report offers a golden opportunity for hospice and palliative care clinicians to assume a leadership role in creating a high-quality, affordable cancer care delivery system, which could also have relevant to other areas of health care, such as cardiology and nephrology where the situation is much the same. Palliative care offers better care and higher quality of care at a cost the nation can afford.

Some specific actions identified in the IOM report that palliative care and hospice care professionals can take immediately, include the following:

- Get involved in the educational and training activities of professional organizations.
- Make donations to the political action sections of professional organizations and volunteer to inform state and national politicians that the palliative care workforce must be expanded.
- Participate in research projects by referring patients to clinical trials and contributing data to learning health care IT systems.
- Participate in performance improvement projects, within local institutions.

The crisis facing the cancer care delivery system is very real and will not be easily solved. Patients and the public will not reduce their demands for more cures, more time, and less toxicity from treatments. Payers will not willingly embrace new models of care without rigorous demonstration of at least cost-neutrality and better quality of care. Governments are unlikely to have additional revenue to spend on cancer in the near future. The good news is that palliative care can help address these issues by providing the type of care that patients and families want at an affordable cost. The IOM report establishes a solid foundation to support better incorporation of palliative care and hospice care into the cancer care delivery system but also presents a challenge to extend this care to the more than 12 million Americans living with a cancer diagnosis and to the 570,000 who die each year of cancer. Ultimately, high-quality cancer care requires the provision of palliative care from the time of diagnoses and timely referral to hospice care at the end of life.

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Author Disclosure Statement

No competing financial interests exist.

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