The Institute of Medicine Report on High-Quality Cancer Care: Implications for Oncology Nursing

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The Institute of Medicine (IOM) issued a pivotal report in 2001 on the quality of health care titled *Crossing the Quality Chasm: A New Health System for the 21st Century* (IOM, 2001). Since that report, numerous factors have accelerated the quest to improve the quality of cancer care, including the demand for evidence-based practice, the focus on patient-centered care, and the growing economic burden of cancer care. In September 2013, the IOM issued a new report on high-quality cancer care, titled *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* (IOM, 2013). Because the number of adults older than aged 65 years will double from 2000–2030, this IOM report gave special attention to the aging population as a significant factor that must be addressed to improve the quality of oncology care.

Because the incidence of cancer is increasing along with the costly interventions to treat it, the quality of this care is a critical component in the growing concern about the future of the healthcare system. An estimated 13.7 million people in the United States currently have cancer, and 1.6 million new cases are diagnosed each year. In addition, more than 570,000 cancer deaths occur each year, and substantial attention has been given to the deficiencies in end-of-life care for these individuals (American Cancer Society, 2012). The 2013 IOM report addresses the quality of cancer care across the trajectory from diagnosis, through treatment, long-term survivorship, and care at the end of life. Figure 1 illustrates this continuum of care.

The IOM convened a committee of interdisciplinary professionals to author the report (including the authors of the current article) and examine the barriers as well as the opportunities for delivering high-quality cancer care and to formulate recommendations for improving the cancer care delivery system. The committee developed a conceptual framework with six components of a high-quality cancer care delivery system (see Figure 2). The model has a few key elements.

- Engaged patients
- An adequately staffed, trained, and coordinated workforce
- Evidence-based cancer care
- A learning healthcare information technology system
- Translation of evidence into clinical practice, quality measurement, and performance improvement
- Accessible, affordable cancer care.

This framework guided the committee’s development of its recommendations (see Figure 3). These recommendations apply across all professions and cancer care settings, yet each has unique application and opportunities for oncology nurses as the largest profession within the oncology workforce. Implementing the recommendations of the IOM report will undoubtedly require interdisciplinary collaboration, professional training, and the commitment of health system administrators. Nurses will play a critical role...
in ensuring the success of this implementation process. Advanced practice nurses will be vitally important, as these changes will require quality improvement efforts to change systems of care.

**Implications for Nursing**

Given both the opportunities and the critical need for nursing leadership to transform the cancer care delivery system (IOM, 2009), the following is a discussion of the committee’s recommendations as they relate to oncology nursing. Each recommendation is presented with commentary regarding its importance to oncology nursing.

**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. The following steps will help to accomplish this.

- The National Cancer Institute (NCI), the Center for Medicare and Medicaid (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 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.

Nurses are well situated to empower patients to communicate their needs, values, and preferences. Patient-centered care is at the core of nursing practice. As new healthcare systems are formed and more multidisciplinary care teams are developed, nurses must take a leadership role in assessing and communicating with patients about their needs and values during each decision point throughout the cancer care trajectory (National Consensus Project for Quality Palliative Care, 2013; Wright et al., 2008).

Since the inception of oncology nursing, patient education and supporting patients and their families during the decision-making process has been a hallmark of the specialty. Because nurses have long been the key participants in designing patient education resources, they should become leaders in developing and evaluating education tools that apply adult learning principles and take advantage of innovative technology (Grant & Ferrell, 2012; IOM, 2008). Also, in the tradition of the nursing profession, nurses should expand their advocacy role to include support for interventions that assist patients with low literacy, language barriers, or other impediments to understand their disease and
treatment options. Advanced practice nurses in areas of staff education or patient and family education can lead efforts in this area.

As policymakers develop innovative payment models to incentivize clinicians to spend more time with patients and families, these proposals must include payments for advanced practice nurses. Requiring clinicians to disclose the costs of care will facilitate patients in making informed decisions. Nurses have an essential role in these discussions and in assisting patients and families with understanding costs and their impact on these decisions. Nurses should provide special care when having discussions about costs with low-income patients, because these patients may decline potentially beneficial treatment because of their inability to pay.

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. The following steps will help 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 patient advanced care plans.
- The cancer care team should place a primary emphasis on providing patients with cancer with palliative care, psychosocial support, and timely referral to hospice care for end-of-life care.
- CMS and other payers should design, implement, and evaluate innovative payment models that incentivize the cancer care team to counsel their patients about advanced care planning and timely referral to hospice for end-of-life care.

Nurses also play an important role in treating patients who have advanced cancer because they have long been leaders in the development of hospice and palliative care services. Although physicians often are responsible for delivery of bad news, nurses provide emotional support to patients and their families when they face a poor prognosis, cope with the emotional repercussions of a cancer diagnosis, and make decisions about treatment options, end-of-life choices, and transition to hospice care (Kelly, Malloy, Munevar, & Virani, 2010). Advanced practice nurses in oncology are increasingly assuming these responsibilities of communicating information regarding diagnosis, prognosis, and treatment options.

Much attention has been given to the communication skills of physicians (Back, Arnold, Baile, Tulsy, & Fryer-Edwards, 2005; Back et al., 2007; Epstein & Street, 2007). The IOM recognizes that nurses also need communication training and education to ensure their expertise in end-of-life discussions and in advanced care planning communication. Several models of nursing communication exist for these types of conversations (Goldsmith, Ferrell, Wittenberg-Lyles, & Ragan, 2013; Wittenberg-Lyles, Goldsmith, & Ferrell, 2013; Wittenberg-Lyles, Goldsmith, Ferrell, & Ragan, 2013). Reimbursement changes also are needed to reward nurses for having these difficult discussions. In addition, models of communication training are needed. This should include communication training across the spectrum from new graduates or those new to oncology to expert oncology nurses and advanced practice nurses.

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. The following steps will help to accomplish this.

- Federal and state legislative and regulatory bodies should eliminate reimbursement and scope-of-practice barriers to team-based care.

Patients

Workforce

Evidence Base to Inform Clinical Care

Patient-clinician interactions

Evidence to Inform Clinical Care

Learning Healthcare Information Technology System

Quality measurement (including patient outcomes and costs)

Accessible, affordable, high-quality care

Performance improvement and new payment methods

Figure 2. A High-Quality Cancer Care Delivery System

• Provide patients and families with understandable information about prognosis, treatment benefits and harms, palliative care, psychosocial support, and costs.
• Provide end-of-life care that meets patients’ needs, values, and preferences.
• Ensure coordinated and comprehensive patient-centered care.
• Ensure that all caregivers have appropriate core competencies.
• Expand the breadth of data collected in cancer research for older adults and patients with multiple comorbid conditions.
• Expand the depth of data collected through a common set of data elements that capture patient-reported outcomes, characteristics, and health behaviors.
• Develop a learning healthcare information technology system that enables real time analysis of data from patients with cancer in a variety of care settings.
• Develop a national quality reporting program as part of a learning healthcare system.
• Implement a national strategy to reduce disparities in access to cancer care for underserved populations by leveraging community interventions.
• Improve the affordability of cancer care by leveraging existing efforts to reform payment and eliminate waste.

Figure 3. Goals of the Recommendations
Note. From Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis (p. 56), by Institute of Medicine, 2013, Washington, DC: National Academies Press. Copyright 2013 by the National Academy of Sciences. Reprinted with permission.

To achieve this vision, education reform is needed. Education in oncology, with few exceptions, has remained in silos with separate training programs held for physicians, nurses, social workers, and others, rather than as interdisciplinary training programs. Given the growing population of older adult patients with cancer, a critical need exists for combining oncology and geriatric expertise (Hurria et al., 2008; Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009). This can begin with nursing professionals. Geriatric nursing expertise, such as care of patients with cognitive impairment, management of comorbidities, prevention of falls, and maintenance of functional status, is critically important in the care of the older adult patient with cancer. Therefore, oncology nursing and geriatric nursing have much to share to ensure that high-quality cancer care is delivered across the trajectory and across the multiple settings of geriatric cancer care (de Moor et al., 2013; IOM, 2009).

Recommendation 4: An Adequately Staffed, Trained, and Coordinated Workforce

Goal: All individuals caring for patients with cancer should have appropriate core competencies. The following steps will help 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 non-oncology 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 finance demonstration projects to train family caregivers and direct-care workers in relevant core competencies related to caring for patients with cancer.

The Oncology Nursing Society (ONS) has been a leader within the nursing profession in establishing certification programs, including advanced practice nurse certification. A need exists now more than ever for increasing the number of oncology-certified nurses and promoting the role of institutions in requiring certification.

Consistent with the aging patient population and the ever-increasing shift to the outpatient setting, family caregivers and unlicensed staff will provide the vast majority of care to patients with cancer. Oncology nurses should lead efforts to develop and implement training for these caregivers (Given, Given, & Sherwood, 2012; Grant & Ferrell, 2012; Northouse, Katapodi,
Schafenacker, & Weiss, 2012). Nursing assistants in long-term care settings are a significant part of the workforce in need of education in delivering care to patients with cancer.

**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. The following steps will help to accomplish this.

- National Cancer Institute (NCI), the Agency for Healthcare Research and Quality, PCORI, and other comparative effectiveness research 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 as many as six months for companies that conduct clinical trials of new cancer treatments in older adults or patients with multiple comorbidities.
- Oncology nurse researchers should play a prominent role in influencing the design of comparative effectiveness research with special consideration to quality-of-life outcomes, symptom management, family perspectives, and other areas of cancer care that are a priority to nurses who treat patients with cancer. Research that includes patient-reported outcomes should be a priority for nursing research as part of the effort to ensure evidence-based, patient-centered care. Nurses should support the greater inclusion of older adult patients with cancer in clinical trials because these patients are more vulnerable to treatment toxicity and complications, and much is unknown about how to effectively treat them (Hurria et al., 2008; IOM, 2008).

**Recommendation 6: Evidence-Based Cancer Care**

**Goal:** Expand the depth of data available for assessing interventions. The following steps will help to accomplish this.

- The 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 capture patient-reported outcomes, relevant patient characteristics, and health behaviors that researchers should collect from randomized clinical trials and observational studies.
- Oncology nurse researchers have influenced cancer research since the 1980s by calling attention to quality-of-life domains that reflect patient physical, psychological, social, and spiritual well-being and by highlighting the importance of these outcome measures in patient decision making. Nurses also have been pioneers in health promotion research in areas such as smoking cessation, breast and ovarian cancer screening, and diet and exercise counseling for cancer survivors. The contributions of oncology nurse researchers are essential to the success of any efforts to define common data elements that best represent the patient experience and that can then be used across clinical research studies.

**Recommendation 7: A Learning Healthcare Information Technology System in Cancer Care**

**Goal:** Develop an ethically sound learning healthcare information technology system for cancer that enables real-time analysis of data from patients with cancer in a variety of care settings. The following steps will help 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 healthcare information technology system for cancer.
- CMS and other payers should create incentives for clinicians to participate in this learning healthcare system for cancer as it develops.
- In all cancer care settings, nurses are central to safety monitoring and performance improvement initiatives. In this era of accountable care, with reimbursement linked to quality performance, nurses have much to contribute to the development and use of quality measures, in particular nursing-sensitive measures that can be used in reporting at the individual, practice, and public level. In addition, as more and more advanced practice nurses work as independent care providers in oncology, they will be in a position to make significant contributions to the learning healthcare systems currently in development. Many opportunities exist for oncology nurses to embrace rapid learning systems that provide efficient feedback regarding nursing practice and its impact on patient outcomes.

**Recommendation 8: Quality Measurement**

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

Many groups of nurses can participate and lead in this endeavor. A learning healthcare system is one in which patient outcome data are rapidly made available to clinicians to allow them to efficiently apply knowledge to future care. Professional nursing societies, such as ONS, should join ranks with the societies of other health professions to develop plans for sharing patient-level data that will build the evidence base needed to ensure the delivery of high-quality care. Nurse researchers can develop and conduct collaborative research to develop the key data points of importance in reporting outcomes related to nursing care. Clinical nursing staff should join in the institutional/practice effort to define, collect, and report the data elements of importance.

Recommendation 9: Accessible, Affordable Cancer Care

Goal: Reduce disparities in access to cancer care for vulnerable and underserved populations. The following steps will help to accomplish this.
• 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.

Nurses have pioneered efforts to address disparities in patient access to high-quality affordable cancer care. As economic challenges, unemployment, an aging society, and other factors contribute to increasing disparities in cancer care, it will be particularly important for oncology nurses to continue to be participants in interventions designed to address the needs of underserved populations (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011; Smith et al., 2009).

Recommendation 10: Accessible, Affordable Cancer Care

Goal: Improve the affordability of cancer care by leveraging existing efforts to reform payment and eliminate waste. The following steps will help 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 based on the best available evidence that aligns with patient 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.

An important example of nurses reducing care with marginal or no benefit is in the growing field of palliative care. Here, strong nursing involvement and leadership have brought to the forefront the importance of eliminating treatments with marginal or no benefit. This example can and should be replicated across the care continuum (Harrington & Smith, 2008; Smith et al., 2012; Weeks et al., 2012). The ultimate aim of palliative care is the provision of care that enhances quality of life and honors patient values and goals.

Conclusion

The IOM report on improving the quality of cancer care is timely given the burdens of a rapidly aging society. As captured in the report title, Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis, the challenge of redesigning cancer care is even more timely amidst healthcare reform.

The IOM report is intended for all oncology professionals, policy makers, reimburers, and systems of care. However, very direct opportunities exist for oncology nurses to lead many of these recommendations: providing patients with understandable information, leading advanced care planning efforts, and redesigning care to provide coordinated and comprehensive patient-centered care. Recommendations 1–3 are examples of work oncology nurses have pioneered.

Oncology nurses are prepared with a strong commitment to evidence-based practice to implement recommendations 5, 6, and 7. Oncology nurses also have a strong record of advocacy for addressing disparities (recommendation 9) and influencing program models that improve quality and eliminate waste (recommendation 10). Advanced practice nurses will be critical to achieving each of the recommendations of the report.

Finally, improving the quality of cancer care begins with oncology nurses. Recommendation 4 calls for ensuring core competency by providers that can be largely achieved through certification in oncology nursing. The final recommendation, 10, calls for rapid learning systems. Oncology nurses at the bedside require access to timely knowledge and opportunities to share their experience to efficiently influence care. The recommendations in the report are broad and challenging. Many will require long-term commitment to achieve. ONS and other oncology organizations will need to
examine these recommendations and develop strategies and timelines for realistic implementation. Collectively, these recommendations can chart the future course of oncology nursing with the ultimate destination of high-quality cancer care.

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