Institute of Medicine Recommendations for Improving the Quality of Cancer Care: What Do They Mean for the General Internist?

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In order to evaluate and address the deficiencies in the U.S. cancer care system, particularly affecting the growing elderly population, the Institute of Medicine (IOM) convened a panel representing oncology providers, surgeons, primary care providers, researchers, policy makers and patients. The Committee concluded that cancer care is on the brink of crisis and issued recommendations targeting all stakeholders involved in cancer care. General internists play a critical role in the care of cancer patients, from the time of diagnosis, through treatment, survivorship and end of life care. We review the IOM recommendations, highlight those that are particularly relevant to the general internist, and outline clinical, research and educational opportunities where general internists should take an expanded role.

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In the United States, more than 1.6 million new cases of cancer are diagnosed each year, and as of 2014, approximately 14.5 million individuals have survived or are living with cancer.¹ It is projected that between 2010 and 2030, total cancer incidence will rise to 2.3 million² and by 2024, the number of cancer survivors will increase to 19 million.¹ Among those newly diagnosed with cancer and those who are living with cancer, most are aged 65 and older and have comorbid medical conditions.¹ Demand for cancer care is growing, driven both by the rise in the incidence of the condition and the aging of the elderly population. However, the oncology workforce is not expected to keep up with the demand.^{3,4} Further, the costs of cancer care continue to increase, outpacing the rise in the costs of care for non-cancer conditions,³ and may begin to account for a greater share of total health care spending.⁵ These factors contribute to a potential crisis in both access and costs, and characterize a cancer care system that is not sustainable. To evaluate and address the deficiencies in the U.S. cancer care system, the

Institute of Medicine (IOM) convened a panel representing oncology providers, surgeons, primary care providers, researchers, policy makers and patients.⁶ The Committee concluded that a high quality, patient-centered, evidence-based health care delivery system must include: engaged patients; an adequately-staffed, trained, and coordinated work force; evidence-based cancer care; a learning health care information technology system; quality measurement and performance improvement; and accessible and affordable care (Fig. 1). The IOM committee issued ten recommendations targeting all stakeholders involved in cancer care (Text Box).

Text Box. Institute of Medicine Recommendations for Improving Cancer Care

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

General internists play a critical role in the care of cancer patients, from the time of diagnosis, through treatment, survivorship and end of life care (Fig. 2). Many of the IOM recommendations are relevant to the general internist, and for several of the recommendations, the general internist plays a central role. We review those recommendations and provide an overview of clinical, research and educational opportunities where general internists can take an expanded role. For a full list of recommendations, please see the report⁴ (also available at: <http://www.iom.edu/Reports/2013/Delivering-High-Quality-Cancer-Care-Charting-a-New-Course-for-a-System-in-Crisis.aspx>).

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Figure 1. High-quality cancer care delivery system. Reproduced with permission from *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, 2013, by the National Academy of Sciences, courtesy of the National Academies Press, Washington, DC.

RECOMMENDATIONS 1 AND 2: ENGAGED PATIENTS

Effective patient–clinician communication and shared decision making are key components of patient-centered care,⁷ relying on informed, activated, and participatory patients

and family members, patient-centered clinicians, and an accessible, well-organized, and responsive healthcare system. However, despite patients’ desire for information, deficiencies persist in patient-centered communication

Figure 2. Trajectory of cancer care and the role of the general internist (*GIM). Figure reproduced with permission from *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, 2013, by the National Academy of Sciences, courtesy of the National Academies Press, Washington, DC. “*GIM” added for this manuscript.

required for shared decision making. The IOM Committee recommended that understandable information be provided to patients and their families, and that this information incorporate estimates of cancer prognosis, treatment options (including benefits, harms and costs), as well as advice about palliative care and psychosocial support. Such personalized information should be discussed at the time of diagnosis and treatment, leading to the creation of a personalized care plan that is revisited (and if needed, revised) along the course of cancer care. To facilitate engaging patients in such discussions, the IOM advised that members of the cancer care team receive comprehensive and formal training in communication. Decision aids aimed at facilitating such discussions in clinical settings should be developed.

While the responsibility for providing prognostic, treatment and cost information belongs to the oncology team, general internists may help patients and families understand the nature of their disease, and provide an overview of their treatment options and healthcare choices. Particularly, they may provide input on how comorbid medical conditions may affect prognosis and, building on continuity relationships, elicit patient preferences and clarify goals of care. This requires that the oncology referral is not a handoff, but instead that the general internist remain integrated into ongoing cancer care. Numerous cancer prognostic tools are available online, and may be readily accessed by general internists and used in office-based settings.^{8,9} As cancer diagnoses are often made in the primary care settings, general internists have an active role in directing referrals to oncology providers who achieve a patient-centered approach to cancer care. Further, general internists can guide patients' interactions with their oncology providers as they discuss these critical aspects of care. In addition to guiding clinical care of patients with cancer, general internists engaged in research (such as those in the Society of General Internal Medicine) may work with oncology colleagues to develop, test and implement decision aids and study the impact of decision making on patient-reported outcomes. Clinician educators should develop and/or promote communication training focused on activating patients for decision making, and ensure that trainees and practicing providers have the skills to engage in shared decision making and cost-related discussions.

The second recommendation also focused on communication and decision making, but specifically targeted those with advanced cancer. The IOM emphasized that patients with advanced cancer must be provided with palliative care, psychosocial support, and timely referral to hospice care for end-of-life care. Prior studies show that patients often have inaccurate perceptions about prognosis, leading to receipt of burdensome treatments

at the end of life,^{10,11} that patients may alter end-of-life treatment requests when adequately informed,¹² and that outcomes may be improved when patients engage in palliative care.¹³ General internists are well positioned to offer a clinical perspective on the overall health status of those with advanced cancer and to discuss end-of-life care.¹⁴ The general internist may also be well suited to revisit prognosis and realign the care plan with patient preferences. The general internist must master discussing advance directives and coordination of care with palliative care specialists and hospice, and can transition care away from oncologists who continue chemotherapy for prognostically uninformed patients with advanced cancer. Resources for promoting communication at the end of life are available,^{15,16} and opportunities exist for internists to advance research and clinical competencies in this area.

RECOMMENDATIONS 3 AND 4: AN ADEQUATELY STAFFED, TRAINED, AND COORDINATED WORKFORCE

Caring for cancer patients often requires a large and diverse team of clinicians including oncology specialists, surgeons, other disease specialists and primary care providers. This may lead to gaps in communication and coordination during cancer treatment, and an ineffective transition following completion of treatment.¹⁷ The IOM emphasized coordination of care between the cancer care team and the primary/geriatrics and specialist care team. Coordination of care can be facilitated by development and sharing of treatment and survivorship care plans. Similar to hospital discharge summaries aimed to enhance transition from inpatient to outpatient settings,¹⁸ survivorship care plans promote joint understanding of the cancer diagnosis, treatment and follow-up needs, including late and long-term effects of cancer treatment and surveillance for recurrences.¹⁷ Further complicating the future of cancer care are the existing and projected workforce shortages for oncology and primary care clinicians.^{3,4,19,20} To achieve efficiencies in caring for cancer patients, inter-professional collaboration is critical and should be promoted by health systems and professional societies.

Internists care for patients across the cancer continuum, and are expected to care for a growing population of cancer survivors. Therefore, they must have appropriate core competencies needed to provide high quality care. While general internists typically communicate with numerous specialists in attempts to coordinate care, there are deficiencies. In addition to achieving core competencies in effective communication and care coordination, general internists should have a core competencies pertaining to

clinical knowledge and skills. For example, recent studies suggest knowledge gaps in late effects of cancer treatment and strategies for surveillance for recurrences.^{21–24} Training is needed so general internists can fully collaborate in the care for patients receiving cancer treatment and during survivorship. Educational programs and resources are available.^{25–27} General internist educators should establish core competencies in cancer care and develop medical school, residency and continuing medical education (CME) curricula. Within academic institutions, health systems and professional societies, general internists should train the workforce in team-based cancer care and promote coordination with oncology care teams. Evaluation of the impact of such training on patient outcomes and costs is needed.

RECOMMENDATIONS 5–8: EVIDENCE-BASED CANCER CARE, A LEARNING HEALTH CARE IT SYSTEM IN CANCER CARE, AND QUALITY MEASUREMENT

Cancer organizations, such as the American Society of Clinical Oncology (ASCO) and the National Comprehensive Care Network, have actively developed and promoted the use of guidelines for delivering cancer care. Over the past few years, ASCO has further encouraged adherence with practice guidelines and continuous quality measurement by practices enrolling in the Quality Oncology Practice Initiative (QOPI) accreditation. Awareness of oncology practice patterns and quality of care may help guide referrals from individual general internists, as well as alignment in accountable care organizations. Further, general internists often practice in environments that may serve as learning healthcare systems that monitor cancer treat-

ment, the interplay with comorbid medical conditions, and the effect of coordinated care on patient-reported and health care outcomes. The Patient-Centered Outcomes Research Institute has been tasked with representing the voices of stakeholders, including physicians. General internists caring for patients along the cancer continuum may engage with the research community (including the health services researchers within the Society of General Internal Medicine) to generate patient-centered, “real world” outcomes and assist with dissemination and implementation of proven interventions.

The IOM committee recognized that cancer clinical trials often exclude elderly patients and those with comorbidities, thus data on representative patients diagnosed with cancer is lacking. As such, the Committee recommended that funded studies include populations that more closely represent “real world” patients with those conditions, that trial data capture patient-reported outcomes, and that the quality of cancer care must be continuously evaluated.

RECOMMENDATIONS 9 AND 10: ACCESSIBLE, AFFORDABLE CANCER CARE

While becoming more personalized, cancer therapy costs are rising despite limited evidence for overall improvement in outcomes. Furthermore, disparities in cancer care continue to persist for those in racial or ethnic minority groups, those with lower socioeconomic status, those who are lesser educated, those with lower health literacy, those who are underinsured or uninsured, and the elderly. In addition to health insurance coverage, other factors contribute to disparities in cancer care,

Table 1. Selected Choosing Wisely Recommendations in Cancer Care for the General Internist

Recommendation	Organization
Don't perform PSA testing for prostate cancer screening in men with no symptoms of the disease when they are expected to live less than 10 years.	American Society of Clinical Oncology
Avoid colorectal cancer screening tests on asymptomatic patients with a life expectancy of less than 10 years and no family or personal history of colorectal neoplasia.	American College of Surgeons
Don't perform CT screening for lung cancer among patients at low risk for lung cancer.	American Thoracic Society
Don't recommend screening for breast or colorectal cancer, or prostate cancer (with the PSA test), without considering life expectancy and the risks of testing, overdiagnosis and overtreatment.	American Geriatrics Society
Don't screen for ovarian cancer in asymptomatic women at average risk.	American College of Obstetricians and Gynecologists
Don't perform routine cancer screening for dialysis patients with limited life expectancies without signs or symptoms.	American Society of Nephrology
Don't perform Pap smears on women younger than 21 or who have had a hysterectomy for non-cancer disease.	American Academy of Family Physicians
Don't perform surveillance testing (biomarkers) or imaging (PET, CT, and radionuclide bone scans) for asymptomatic individuals who have been treated for breast cancer with curative intent.	American Society of Clinical Oncology
Avoid using advanced imaging technologies—PET, CT and radionuclide bone scans—to monitor for a cancer recurrence in patients who have finished initial treatment and have no signs or symptoms of cancer.	American Society of Clinical Oncology

PSA prostate-specific antigen, CT computed tomography, PET positron emission tomography

including out of pocket costs (e.g., copays, deductibles, transportation) and lack of access to high quality care delivery systems (i.e., distance to treatment facilities). Cancer care costs burden patients. Cancer patients are more than twice as likely to go bankrupt compared to those without cancer.²⁸ Despite the implementation of the Affordable Care Act, many cancer patients are likely to continue to experience inadequacies in care. The IOM Committee recognized that community-based interventions may be best equipped to promote quality of cancer care and recommended mechanisms to identify, support and disseminate such interventions. General internists must continue to work with governmental agencies and professional organizations to reduce disparities and inefficiencies in health care. They should focus clinical, educational and research initiatives on underserved populations and engage with communities, reaching beyond the health care system. With the implementation of the Affordable Care Act (ACA), general internists who engage in health services research are well positioned to test the effect of the ACA on patient-oriented outcomes and costs of care.

The IOM committee emphasized the need to eliminate waste in cancer care and thereby improve affordability. Specifically, professional societies should evaluate the evidence behind testing procedures, disseminate proven methods and actively discourage practices where there is no evidence or where the harms may outweigh the benefits. Many of the “Choosing Wisely” recommendations²⁹ pertain to cancer care and are of relevance to general internists. (See Table 1).

In summary, to help fix the broken cancer care system, general internists need to play a central role in coordinating care for the patient newly diagnosed with, receiving active treatment for, and having survived cancer. Well qualified, general internists who recognize their role in collaborating in and coordinating care for cancer patients will facilitate cancer treatment that is contextualized to a patient’s overall health, promote patient-centered care by supporting informed decision-making across the cancer trajectory, and permit oncology teams to focus their efforts on active treatment, thus making cancer care maximally effective and efficient.

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