

‘Dying in America’: implications for oncology of the recent IOM report

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Those of us who work in clinical oncology are used to thinking about how to improve care for our dying patients. We may be less familiar with efforts to extend the benefits of palliative care to patients and families facing other kinds of advancing catastrophic illnesses, such as lung, cardiac, and neurologic diseases. In September last year, the Institute of Medicine of the National Academies released a report titled *Dying in America: improving quality and honoring individual preferences near the end of life*.¹ This ambitious work encompasses the needs of all patients with potentially lethal illnesses, not just cancer. The report’s 5 key findings are:

- *Person-centered, family-oriented palliative care should include extra efforts to manage transitions, avoid unneeded hospitalizations, and support family caregivers.* Palliative care should be involved earlier in the disease trajectory and more often during the course of the disease.
- *Clinician-patient communication and advance care planning should be prioritized and improved to ensure that patients have opportunities to articulate their preferences while they are still able to.* Those efforts should be undertaken serially to maximize clarity of the patient’s wishes and they should be incentivized by health systems and practices.
- *Professional education and development needs to include extension of the new discipline of hospice and palliative medicine into medical and nursing school curricula, across professional silos, and to include improving physician communication skills.* “Primary” palliative medicine skills must be transferred to all practitioners.
- *Policies and payment systems must be reorganized to incentivize care coordination and palliative care provision, and to discourage excessive use of inpatient days and multiple care transitions.* Related quality standards and measures must be innovated.
- *Public education and engagement about end-of-life care is crucial; efforts must be made to normalize conversations about death and dying.*

Clinical oncology is no longer the only domain in western medicine in which advance care planning and pallia-

tive care make obvious sense, but it could be argued that oncologists have been at it long enough that we should be leaders. And although there are cancer treatment settings in which optimal integration and access to palliative care services are the standard, there are many others in which there is scant evidence of progress.

In fact, the practical reality remains that palliative care services in North American cancer treatment settings are inadequate to meet the basic clinical needs of our patients. In a 2010 review, investigators reported that only 59% of National Cancer Institute-designated comprehensive cancer centers and 22% of community cancer centers had outpatient palliative care programs.² In a more recent survey of all 377 acute care hospitals in California, 24 of the 136 (18%) that provided adult inpatient palliative care services also provided outpatient services, of which only 25% were available 24/7; the numbers were even less encouraging for pediatric patients.³ This step-off

in service availability undermines a core element of the IOM recommendations (easy availability and 24/7 access to services, not just for hospice or inpatients) and unmask a basic problem in the delivery of outpatient oncology care in the United States and Western countries: in general, we are not organized to provide around the clock service. With few exceptions, outpatient oncology practices define their “open” hours within the ordinary confines of the work-day, and after hours sign off the care of their patients to on-call physicians and emergency departments or urgent care centers.

Yet there are compelling examples of systems of cancer care organized around the idea that services should be delivered in the cancer center whenever the patient needs them. In some settings, 24/7 outpatient infusion services are available for patients who require blood products, chemotherapies, antibiotics, and other treatments, and these settings can be used also for after-hours palliative care symptom management problems, with attendant avoidance of emergency department visits and hospitalizations.⁴ Cancer centers were among the first complex disease management entities to introduce patient navigators, to inte-



grate psychosocial and spiritual care into the treatment environment, and to assure ready access to pain management services. Leading oncology organizations were early adopters of distress management guidelines, pain management quality measures, and a host of related evidence-based algorithms for palliating burdensome symptoms.

It is time for organized oncology to further extend our efforts and to help lead Western medicine toward fulfilling the challenges of the IOM report. Our field has the knowledge and the skills, and perhaps, partnered with professional⁵ and lay⁶ advocacy organizations and legislative champions, we can find the resolve as well. As we begin the new year, the Editors and staff of THE JOURNAL OF COMMUNITY AND SUPPORTIVE ONCOLOGY wish you the very best.

References

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