

GUEST EDITORIAL

End-of-Life Care: Crossing the Bridge from Treatment to Support

With the aging population in the United States projected to reach 83.7 million by 2050, it is more important than ever to ensure that sufficient resources and services are available to support patient-centered palliative care. The quality and costs of end-of-life care can be improved through difficult but honest discussions, shared decision-making and financial reimbursement with incentives to support implementation of advance care plans that reflect patients' wishes.^{1,2}

Over the past four decades, our knowledge regarding the aging process, extended longevity, and end-of-life treatments has expanded tremendously.¹ The spectrum of sophisticated diagnostics and innovative procedures for managing illness and delaying death have served to strengthen the traditional medical paradigm of paternalistic care in a death-averse society. "[S]cientific advances have turned the process of aging and dying into medical experiences, matters to be managed by healthcare professionals...and we... have proved alarmingly unprepared for it," writes noted surgeon and author Dr. Atul Gawande, who explores these issues through professional practice, research, and personal experiences in his recent book, *Being Mortal*.²

There is national concern for the significant costs—economic and otherwise—associated with continued aggressive care for serious and terminal illness to patients, families and health systems. Research and clinical evidence demonstrates the value of engaging patients and families in discussions about current clinical status, treatment options, patient preferences,

and designation of surrogate decision makers in advance care plans. To that end, leading organizations, including the National Quality Forum (NQF), the Institute of Medicine (IOM), the American Society of Clinical Oncology (ASCO), and the National Hospice and Palliative Care Organization (NHPCO) have identified advance care practices (including integrated palliative care) as major quality indicators associated with good end-of-life care.

Treatment teams grapple with incorporating objective quality measures, due to complex and competing options, which often arise during time-sensitive situations. Clinicians are frequently confronted with time constraints, as well as uncertainty about treatment outcomes and prognosis. This has led to repeat hospitalizations and intensive care stays associated with invasive services that are of limited benefit, and delayed decisions for transitions to supportive and comfort care, prolonged suffering, diminished quality of life and extended bereavement for families.^{1,2} Additional challenges exist in those situations where patients have not communicated their preferences about end-of-life care and support.²

Discussing end-of-life care where prognoses are poor and recommended treatment options are limited, uncertain, or have been exhausted is difficult but necessary for patients, families and healthcare professionals.² Clinicians have reported a lack of experience broaching these topics, a sense of incompetency or failure to facilitate 'better' outcomes, and emotions about our their mortality as contributing factors.² Dr. Susan D.

Block, a palliative care expert at the Dana-Farber Cancer Institute and the Harvard Medical School Center for Palliative Care, recommends also asking patients about their values and cultural beliefs; concerns about what to expect; trade-offs they are willing to make; how they want to spend their time if their health worsens; who they want to make decisions on their behalf if their health worsens and end-of-life preferences.^{2,3,4} Over the course of illness, patients, families and caregivers can assess and revise care plans through shared decision making. Patients may choose to decline recommended treatments, seek alternative treatments and/or discontinue all treatment to achieve their best quality end-of-life. Key decisions should be documented in advance care plans, including legally executed documents (e.g., health care proxy, durable power of attorney, living will).

It is just as imperative to consider the ethical issues inherent in end-of-life planning as it is to address the clinical challenges—both in training and practice.⁴ Clinicians must respect patients' choices and accept those decisions, even when they conflict with their professional or personal judgment about recommended care and avoiding harm.² While patients may not have the medical expertise to independently choose the most appropriate treatment options, they have the legal and ethical prerogative to define what their highest quality of end of life will be and when.

Martha C. Romney, BSN, MS, JD, MPH
Assistant Professor
Jefferson School of Population Health
Martha.Romney@Jefferson.edu

CONTINUED ON PAGE 2

REFERENCES

1. Wolf SM, Berlinger N, Jennings B. Forty years of work on end-of-life care – from patients' rights to systemic reform. *NEJM* 2015;372(7):678-682.
2. Gawande A. *Being Mortal: Medicine and What Matters in the End*. Metropolitan Books. Henry Holt and Company. New York. 2014.
3. Bernacki RE, Block SD. Serious illness communications checklist. *AMA J Ethics*. 2013;15(12):1045-1049.
4. Block S. Assuring safe passage: moving conversation about end-of-life upstream. [Achieving Communication Excellence [ACE] Lecture Series. Interpersonal Communication and Relationship Enhancement. March 27, 2011. <http://www.mdanderson.org/transcripts/assuring-safe-passage-moving-conversation-about-end-of-life-upstream---md-anderson-cancer-center.htm>. Accessed March 15, 2015.