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Ernlé W. D. Young

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IMPROVING CARE FOR THE END OF LIFE: A SOURCEBOOK FOR HEALTH CARE MANAGERS AND CLINICIANS

By Joanne Lynn, Janice Schuster, Anne Wilkinson, and Lin Noyes Simon.
2nd ed, 464 pp, \$49.95.
New York, NY, Oxford University Press, 2007.
ISBN-13 978-0-1953-1042-9.

AS THE AUTHORS CLAIM IN THEIR PREFACE, “THIS SOURCEBOOK features . . . strategies to improve care, with a focus on those that any manager of any healthcare system can try almost immediately” (p xi). This is not a vain promise but one inherently kept in the pages that follow:

Part I . . . suggests quality improvement methods that every organization can use right now; Part II focuses on changes that patients and families often demand or would benefit from; Part III describes environments that encourage better practice [such as taking heed of caregivers and having in-house palliative care services or units from which consultations can readily be obtained]; and Part IV discusses opportunities for change in caring for patients with specific diseases. (p xii)

Health care professionals are encouraged to be sensitive to the trajectories typically followed by persons with life-threatening illnesses, ie, a more or less acceptable quality of life followed by a relatively short period of decline, as is the case with many types of cancer; long-term limitations with a steadily declining quality of life and intermittent acute episodes, as in organ system failure; and prolonged dwindling accompanied by frailty, as characterizes Alzheimer disease and other dementias. Awareness of these contrasting trajectories and of what makes for improved care for patients with different illnesses in different settings is essential for ongoing quality improvement.

Since improvement is not serendipitous, the primary methodology centers around plan-do-study-act cycles—ie, setting aims for improvement, measuring how these aims have been met, reviewing actual performance data, and then developing and testing changes in light of these findings. These are the building blocks of creative innovation. As Figure 2.1 (p 21) indicates, these cycles may be simultaneous or sequential. For example, improving ventilator withdrawal may be broken down into separate objectives: communicating better with families prior to and during ventilator withdrawal; the actual ventilator weaning process; and ensuring that patients are comfortable and free of anxiety, fear, or distress while the ventilator is withdrawn. Ideas for addressing these issues may be tried and tested either at the same time or sequentially, with each building on what went before.

The authors present a comprehensive model of caring for the whole person—medically, emotionally, and spiritually. They go on to discuss discrete topics with practical and helpful examples. Among these are preventing, assessing, and treating pain (chapter 3—though here, unfortunately, the opportunity is missed to distinguish physical pain from existential pain requiring spiritual and emotional support); managing dyspnea and ventilator withdrawal (chapter 4); advance care planning for all stages of health and disease (chapter 6—though here, too, the authors do not stress the importance of obtaining a personal value statement from patients, such as “These are the qualities and capacities in my life that I value; should these capacities and qualities be lost to me, any or all of the following treatments would be unwanted. . . .”); and ensuring continuity and coordination of care from each sector of the health care system to the next (chapter 7)—a crucially important topic, given that frequently the right hand does not know what the left did or is doing.

The authors envision opportunities for quality improvement in specific diseases: dementias (chapter 11), cancer (chapter 12), depression and delirium (chapter 14), and advanced heart or lung failure (chapter 13). Obviously, this list is representative rather than exhaustive. Other terminal conditions, and the trajectories unique to each of them, require more research followed by plan-do-study-act cycles. Among these, for example, would be amyotrophic lateral sclerosis, Parkinson disease, anorexia nervosa, multiple sclerosis, and muscular dystrophy.

The current edition presents proven strategies for improvement from a range of health care organizations as disparate as hospice and the intensive care unit, the skilled nursing facility, and the emergency department. Accordingly, this volume provides busy front-line clinicians and case managers with abundant resources for tangible contributions to the well-being of patients who are confronting the end of life. But given the fact that life itself is a terminal condition, the book becomes essential reading, not only for patients and their caregivers, but for all who, sooner or later, whether they like to think of it or not, might require the care of dedicated health care professionals.

Ernlé W. D. Young, PhD
Stanford University (Emeritus)
eyoung@stanford.edu

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