Quality End-of-Life Care: Where Do We Go from Here?

PETER A. SINGER, M.D., M.P.H., F.R.C.P.C.,1 DOUGLAS K. MARTIN, Ph.D.,1 and KERRY BOWMAN, M.S.W., Ph.D.2

THE RIGOROUS STUDY by Emanuel and coworkers reported in this issue of the Journal underlines two critical points in relation to end-of-life care. First, the various "pieces of the puzzle" at the end of life—for example, pain control, advance care planning, and palliative care—should be integrated into a coherent conceptual framework of quality end-of-life care. Second, the appropriate evidence base for this framework is derived from patients' perspectives. After exploring these two points, we make two further observations about next steps in improving quality end-of-life care: we need to develop a quality improvement strategy at the organizational and health system level, and we need to focus on quality end-of-life care not only in developed countries but also throughout the world.

The first point has now been made by at least five groups—a consortium of organizations that published a position paper in *Journal of the American Geriatric Society,*1 the Institute of Medicine Committee on End-of-life Care,2 our research group,3 Steinhauser et al.,4 and Emanuel and Emanuel both in this article and in an earlier publication.3 The underlying assumption is that to make gains in quality of end-of-life care, "lumping" (addressing the problem of end-of-life care as an integrated whole) is better than "splitting" (addressing the various "pieces of the puzzle" in isolation). The extent to which this assumption proves true remains to be seen. However, it is obvious that the quality gains related to "splitting," which is the predominant research approach in end-of-life care, has led to disappointing results in the quest to improve end-of-life care. The "nail in the coffin" of the "splitting" strategy was probably the SUPPORT trial.

The second point has been put forth by three of these groups: our research group, Steinhauser and colleagues, and Emanuel and colleagues. We conducted in-depth qualitative interviews of patients receiving dialysis, people with human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), and residents of a long-term care facility to identify five elements of quality end-of-life care: adequate pain and symptom control, avoiding inappropriate use of life-sustaining treatments, achieving a sense of control, relieving burdens on loved ones, and strengthening relationships with loved ones.3 Steinhauser et al.4 used qualitative focus groups and interviews with providers, bereaved family members, and patients with cancer and HIV to identify six elements of quality end-of-life care: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person. Emanuel and Emanuel used factor analysis of survey data from terminally ill patients, the majority with cancer, to identify eight elements of quality end-of-life care: patient-clinician relationship, social connectedness, caregiving needs, psychological distress, spirituality/religiousness, personal acceptance, sense of purpose, and clinician communication. Significantly, the survey questions in the Emanuel and Emanuel study also arose initially in focus groups with patients and providers. Because the frameworks are based on

---

1University of Toronto Joint Centre for Bioethics, Toronto, Ontario, Canada.
2Mount Sinai Hospital, Toronto, Ontario, Canada.
patients' perspectives, and patients are the valid informants for quality end-of-life care, the frameworks all have validation built into their development.

While there are many similarities among these three frameworks, (e.g., all three include at least one item concerning relationships with others), the three studies use somewhat different methods to develop an integrated, patient-based, conceptual framework for quality end-of-life care and their results differ. For example, the Emanuel and Emanuel framework omitted pain and other physical symptoms because the dimension “either had too few items or ... low reliability.” This nicely illustrates the counter-intuitive results that may arise with factor analysis. A clinician confronted by this result should say, “Eigenvalue, Smeigenvalue! Any framework of quality end-of-life care that excludes pain and other symptoms just doesn’t cut the mustard.”

This is not meant as a critique of the Emanuel and Emanuel framework, but rather an illustration of the fallibility of any of the three studies. Our study has been criticized, and we believe rightly so, for the omission of an element related to spirituality. Because we have these three related frameworks, the next step really ought to be to combine them so each can supplement the deficiencies of the other. Combining the three frameworks in a sort of “meta-analysis” will yield a single, more generalizable, conceptual framework of quality end-of-life care from the patients’ perspective.

But what is that good for? Presumably we are all interested in describing the phenomenon of quality end-of-life care in order to improve it. A patient-based conceptual framework of quality end-of-life care can be used to develop measures of quality end-of-life care that should be reliable, valid, and extremely simple to complete. In this regard, the work by Emanuel and Emanuel is further ahead than the other two groups because they have an existing survey instrument. Another available instrument is the “toolkit” developed by Joan Teno. Ultimately, these efforts will yield a report card approach to quality improvement in end-of-life care.

This will be a major improvement over our current situation. At the moment, we have no systematic information about the quality of end-of-life care received (outside hospice settings) in health care institutions, by populations, or in health systems. This information gap is a major barrier to broad-based improvement efforts in end-of-life care.

We suspect that report card approaches will have some effect on quality of end-of-life care. Imagine a chief executive confronted with evidence of “C-quality” end-of-life care at a hospital board meeting—things will change in that hospital. Imagine a health minister seeking re-election faced with population-based evidence of “C-quality” end-of-life care in his or her province. Information itself, delivered in the appropriate context, probably does change organizational behavior.

Other quality improvement methods, however, may enhance the effectiveness of end-of-life report cards. One of the weaknesses of the report card strategy is that it relies on information alone to change behaviour. Other strategies, such as rapid cycle change, rely less on measurement and focus more on changing care. Indeed, one of the important recent advances in medical ethics has been the marriage of end-of-life care and organizational improvement strategies in the Institute for Health Care Improvement Breakthrough Collaborative on End-of-Life Care led by Joanne Lynn. Moreover, it may be that systematically eliciting the perspectives of dying patients and feeding them back to the care team and senior management, without any systematic measurement efforts, would be effective in improving care. Ultimately, empirical evaluation should guide the best balance among this mix of quality improvement strategies in end-of-life care.

So, let’s imagine we have an operational quality improvement strategy, based on patients’ perspectives and evaluation of the appropriate mix of quality improvement strategies, at the organizational and health system levels. What will be left to accomplish?

Nothing much—just broadening our focus from the 8 million deaths that occur in developed countries to the other 46 million deaths in low and middle income countries. End-of-life researchers have been astonishingly myopic in their approach to this problem. Of the hundreds of articles published each year on end-of-life care, it is extremely difficult to find those few that focus on developing countries where, in fact, most people die. The developed world probably has much to teach in the area of pain and symptom control (including regulatory regimes for narcotics) and much to learn in the area of cultural, religious, and psychosocial means of coping with death.
Learning these lessons will require sensitive approaches to the problem of cultural difference; these approaches are also helpful of course within developed countries.

Our ultimate goal should be to improve the quality of end-of-life care not only for the 8 million people dying in rich countries but for all 54 million people dying annually in the world. We will know we are approaching that goal when the World Health Organization devotes an annual edition of its World Health Report—or even a chapter of one—to the problem of end-of-life care, and when indicators of quality of end-of-life care appear in the appendix among indicators of health system performance routinely collected from member states.

ACKNOWLEDGMENTS

Peter A. Singer is Sun Life Chair in Bioethics and Director, University of Toronto Joint Centre for Bioethics; Professor of Medicine, University of Toronto; Canadian Institutes of Health Research Investigator; and Associate Editor, Canadian Medical Association Journal. Douglas K. Martin is Research Associate, University of Toronto Joint Centre for Bioethics. Kerry Bowman is Bioethicist, Mount Sinai Hospital, University of Toronto Joint Centre for Bioethics, and Assistant Professor of Family and Community Medicine, University of Toronto.

Dr. Singer is supported by an Investigator award from the Canadian Institutes of Health Research.

REFERENCES


Address correspondence to:
Peter A. Singer, M.D., M.P.H., F.R.C.P.C.
University of Toronto Joint Centre for Bioethics
88 College Street
Toronto, Ontario M5G-1L4
Canada
E-mail: peter.singer@utoronto.ca