



## Patient safety deserves better response

In Wayne Kondro's article<sup>1</sup> about our report to Health Canada on governance for patient safety,<sup>2</sup> Ross Baker suggests that a national patient safety agency probably isn't feasible in Canada because jurisdiction over health care is fractured. But surely that doesn't mean it is not worth doing.

It did not take very long for either the Public Health Agency of Canada (PHAC) or the Health Council of Canada to be set up. Given that the Canadian Patient Safety Institute already exists, changing its name to the Canadian Patient Safety Agency, changing its position within the Health Canada organizational chart and clarifying its mandate should not be difficult. The main point is that Canada, like other countries, has a patient safety problem of sufficient magnitude to deserve a substantive national response. The current agenda for patient safety is itself fragmented and piecemeal precisely because there is no guiding agency to coordinate the work being done.

The PHAC was set up because of the SARS crisis in Toronto, the Walkerton problem and the threat of other infections (e.g., avian flu), none of which has had the impact that adverse events have every day in Canada. Its mandate is to provide, in collaboration with the provinces and territories, a coordinated response to these threats. To date there appears to be little concern over the

complexities of PHAC's relationships with other jurisdictional bodies.

It seems to us that if there is a will to create a more comprehensive agency to tackle the problem of adverse events, a way can be found to do so. We do our patients and their families a disservice if we fail to ensure, to the degree possible, patient safety in our hospitals and other health care facilities and programs.

**Sam Sheps**  
**Karen Cardiff**  
University of British Columbia  
Vancouver, BC

### REFERENCES

1. Kondro W. Independent federal safety board needed to prevent adverse events. *CMAJ* 2006;174(12):1699-700.
2. Sheps S. *Governance for patient safety: lessons from the non-health risk-critical high-reliability industries*. Ottawa: Health Canada; 2005.

DOI:10.1503/cmaj.1060149

## End-of-life care in Canada

In their article about end-of-life care, Daren Heyland and associates<sup>1</sup> conclude that trusting, communicative relationships between physicians and seriously ill patients and family members are key to quality end-of-life care, but they offer few suggestions on establishing such relationships; instead, they advocate more research.

Educational programs to promote communication between health practitioners and dying patients already exist and appear to improve attitudes toward and engagement with those who are dying.<sup>2-4</sup> Physicians without such training, however, may avoid end-of-life discussions because of time constraints, financial disincentives, concerns about legal implications or the feeling that they are inadequately prepared.<sup>5,6</sup> Families may not even realize that they have a choice about life-support measures unless they inform themselves about their loved one's condition and assertively insist upon discussions with

the responsible physician; as such, there may be inadvertent discrimination against less educated or acculturated families.

The authors' statements questioning the value of living wills and additional home care capacity<sup>1</sup> may also be misleading. Their findings suggest, rather, that such measures are inadequate. Trained professionals are needed, for example, to help families decide when to honour living wills — when to allow more time on life support in case meaningful recovery is possible, and when it is medically reasonable to stop; when to continue treatment in an acute care hospital as opposed to a chronic care facility or at home. Near the end of a person's life, emotions run high and discerning what is reasonable is often difficult without the help of professionals.

In addition, "quality end-of-life care" is not dictated entirely by physician-patient relationships. Hospital support is needed to implement palliative care appropriately<sup>5</sup> and to ensure consistency of care. Patients staying on units where death occurs infrequently, for example, may not receive the same standard of care as those staying on oncology units, where staff are typically better trained in palliative measures. Palliative care may be interpreted as "no care" in some settings, which can result in dying patients spending their final hours unkempt, uncomfortable and alone. Tailored care may also be difficult to achieve when hospital policies are rigidly applied, as when (for example) family members are prevented from visiting, without regard for the dying patient's wishes or well-being.

Practical suggestions consistent with this study's findings might include training in end-of-life care at the undergraduate and graduate levels for all medical personnel, ensuring adequate compensation for this often time-consuming work, hospital-wide minimum standards for palliative care, guidelines for tailoring of care in end-of-life situations and hospital-wide ac-

cess to multidisciplinary palliative care teams.

In conclusion, rather than more research, we may need more education, more practical solutions and more compassion.

### Katharina Manassis

Department of Psychiatry  
Hospital for Sick Children  
Toronto, Ont.

#### REFERENCES

1. Heyland DK, Dodek P, Rocker G, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006;174(5):627-41.
2. Fischer SM, Gozansky WS, Kutner JS, et al. Palliative care education: an intervention to improve medical residents' knowledge and attitudes. *J Palliat Med* 2003;6(3):391-9.
3. McClement SE, Care D, Dean R, et al. Evaluation of education in palliative care: determining the effects on nurses' knowledge and attitudes. *J Palliat Care* 2005;21(1):44-8.
4. Smith-Cumberland TL, Feldman RH. EMTs' attitudes toward death before and after a death education program. *Prehosp Emerg Care* 2006;10(1):89-95.
5. Alaeddini J, Julliard K, Shah A, et al. Physician attitudes toward palliative care at a community teaching hospital. *Hosp J* 2000;15(2):67-86.
6. Pereira GJ. Palliative care in the hinterlands: a description of existing services and doctors' attitudes. *Aust J Rural Health* 2005;13(6):343-7.

DOI:10.1503/cmaj.1060101

The recent study by Daren Heyland and associates<sup>1</sup> provides excellent insight into the wishes and priorities of seriously ill patients and their family members. The authors note that the perception of "what matters most" in end-of-life care varies widely between different patient groups and their family members, which indicates the need for individualized care.

In our own medical oncology practice we find that this variability in "what matters most" exists not only between patient groups but also at different stages of a patient's illness. The large discrepancy between desired and actual place of death for patients with metastatic breast cancer may be an example of this. Our data for patients who died with this disease revealed that 71% wished to die at home, but only 33% were able to do so.<sup>2</sup> This difference probably reflects a complicated combination of the difficulties in coordinating palliative care services and changing perceptions of and decisions

about end-of-life care by patients and their caregivers as the patients' condition deteriorates. Therefore, decisions and communication about end-of-life care not only need to be individualized, but also need to be reassessed frequently.

Hopefully, through awareness of these key issues, we can improve the quality of end-of-life care for all terminally ill patients.

### Christine Simmons

#### Mark Clemons

Division of Medical Oncology  
Sunnybrook and Women's College  
Health Sciences Centre  
Toronto, Ont.

#### REFERENCES

1. Heyland DK, Dodek P, Rocker G, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006;174(5):627-41.
2. Clemons M, Zalany L, Marcus T, et al. Dying with breast cancer - an audit [abstract]. *J Clin Oncol* 2005;23(16S):7678.

DOI:10.1503/cmaj.1060096

#### [Three of the authors respond:]

Katharina Manassis seems to take exception to our call<sup>1</sup> for more research in the area of end-of-life care, suggesting that "more education, more practical solutions and more compassion" are what are required to fix the problem. Although this is true, we believe it is not sufficient. Most of the patients we serve at the end of life (and their families) are very dissatisfied with the care they receive.<sup>2</sup> Overall, we do agree that more educational and clinical resources need to be applied to caring for patients with terminal and chronic diseases. In this regard, we are pleased that Associated Medical Services of Ontario has stepped forward to fund fellowships in end-of-life care in Ontario teaching hospitals.<sup>3</sup> The fellows will endeavour to promote excellent care of the terminally ill, quality improvement initiatives and curriculum developments that will ultimately translate into improved care for these patients.

However, as a discipline, palliative and end-of-life care, relative to other medical disciplines, stands on a weak

evidentiary basis informing us about best practice and how it is optimally achieved in various circumstances. We think it is misguided to assume that we now have all the solutions to quality-of-care problems in our health care system. Accordingly, the Canadian Institutes of Health Research (CIHR) has allocated over \$14 million to establish end-of-life research teams across the country and has recently dedicated a specific committee to review all grants in this area.<sup>4</sup> These positive developments increase the likelihood that future educational and clinical interventions will be supported by substantial research evidence.

We agree with Christine Simmons and Mark Clemons that communication and decision-making at the end of life are best viewed as a process, not an event, which requires frequent reassessments. Unfortunately, our fragmented, discontinuous health care system makes this kind of care challenging. We hope that future research by the Canadian Researchers End-of-Life Network and other CIHR-funded teams will illuminate the strategies needed to optimize communication and decision-making for dying patients and their families.

### Daren K. Heyland

Professor of Medicine  
Queen's University  
Kingston, Ont.

### Graeme Rocker

Professor of Medicine  
Dalhousie University  
Halifax, NS

### Deb Pichora

Project Coordinator  
Canadian Researchers End-of-Life  
Network (CARENET)

#### REFERENCES

1. Heyland DK, Dodek P, Rocker G, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006;174(5):627-41.
2. Heyland DK, Groll D, Rocker G, et al. End of life care in acute care hospitals in Canada. A quality finish? *J Palliat Care* 2005;21(3):142-50.
3. AMS educational fellowship in care at end of life. Toronto: Associated Medical Services; 2005 May 10. Available: www.ams-inc.on.ca/default.html (accessed 2006 Jul 24).
4. Rocker GM, Heyland DK. New research initiatives in Canada for end-of-life and palliative care [editorial]. *CMAJ* 2003;169(4):300-1.

DOI:10.1503/cmaj.1060132