

## Enhancing the quality of end-of-life care in Canada

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Currently, approximately 240 000 Canadians die each year, about 90% as a result of a prolonged illness. Given our aging population, it is estimated that by 2020 there will be 40% more deaths annually than in 2003.<sup>1</sup> For dying Canadians, there are well-documented gaps between the end-of-life care people prefer and the care that they actually receive. Narrowing these gaps is a pressing public and professional priority.

Improving the concordance between desired and provided end-of-life care will require more honest and timely conversations about goals of care with patients, their families and the members of their health care team. Recently, 278 acutely ill elderly Canadians with advanced chronic disease and their families were interviewed in 12 hospitals.<sup>2</sup> Over three-quarters of patients had thought about end-of-life care and had discussed it with a family member, but they rarely engaged in such conversation with a member of their health care team. Agreement between patients' treatment preferences and their medical record documentation was only 30%. Most discordance reflected their preferences for less-intensive management at the end of life when their medical records actually included plans for full cardiopulmonary resuscitation and technological support in the event of life-threatening illness in hospital.

When asked about what features of quality end-of-life care they considered to be important, seriously ill Canadian patients in hospital and their family members highlighted trust in the treating physician, avoidance of unwanted life support, effective communication, continuity of care, and life completion.<sup>3</sup> Customized approaches to improving an individual's care can be constructed by contrasting individual satisfaction ratings of elements of end-of-life care with the importance of those same elements. The Canadian Health Care Evaluation Project (CAN-HELP) questionnaire is a validated tool that can be used to measure satisfaction with end-of-life care.<sup>4</sup> At a population level, juxtaposition of importance and satisfaction ratings can identify high priority targets for the quality improvement of our health care system. Preliminary evidence suggests that targets include more widespread

strengthening of patient–physician relationships, enhanced communication and better decision-making, including advance care planning.

Advance care planning is an organized process of communication to help individuals and families understand, reflect upon and discuss the goals, values and beliefs for future health care decisions, particularly in the event of future inability to communicate. Advance care planning has the potential to increase patient-centred care by aligning patient preferences with the care they receive, while reducing caregiver burden and unwanted health care expenditures at life's end. Recently, 2 national initiatives have been launched to improve the quantity and quality of advance care planning in Canada: the “Speak Up” campaign, targeted toward the lay public, and the “Just Ask” campaign, targeted toward health care professionals.<sup>5</sup>

The preferences of some people for end-of-life care include a desire to die at home. Accordingly, many Canadians provide domestic care to dying family members or friends. Palliative caregiving can create treasured memories, profound intimacy and a deep sense of accomplishment. However, in one study, family caregivers felt unprepared and underresourced to minister palliative care in their homes.<sup>6</sup> Short- and long-term depression, anxiety and posttraumatic stress disorder are prevalent in family members of decedents, but this can be ameliorated by timely, high-quality communication during the dying process.<sup>7</sup>

Further, the nature of some deaths may exceed caregivers' ability to cope while caring for their loved one at home. This often results in admission to hospital in the final months, weeks or days of life, underscoring the importance of institutional initiatives to improve end-of-life care. Another approach is residential hospice care, where the patient–family caregiver dyad is

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### KEY POINTS

- Narrowing the gaps between the end-of-life care that patients prefer and what they actually receive should be a national priority.
- The quantity and quality of advance care planning needs to be improved.
- Burdens to family caregivers must be acknowledged and addressed.
- Physicians in training need more and better education about palliative care.

the unit of care. As an alternate setting for patients unable to remain at home until death and for those who do not require or desire acute hospital care, hospices help to avoid the “medicalization of death,” while offering holistic family-centred care, as well as ongoing symptom assessment and treatment.

Within a multidisciplinary team, physicians can play a pivotal role in providing quality end-of-life care, wherever it occurs. Along with access to dedicated palliative care consultations and services, all practicing physicians need some skills in palliative care. The development of such skills is crucial for residents, who need more exposure encoded in their national training programs and adapted to their future roles, particularly given the incoming limited work hours and frequent handovers that will threaten the continuity of care. More so than didactic teaching, experiential, case-based, patient-centred curricula for hands-on learning about the practical and ethical aspects of palliative care may help to develop effective communication and counselling skills. Observing expert role models, receiving facilitated feedback and proceeding gradually toward supervised responsibility for leading such discussions<sup>8</sup> should result in enhanced end-of-life care by future physicians.

Myriad statements and studies produced in Canada urge, on paper, efforts to enhance quality end-of-life care. Action is long overdue. More advance care planning, enhanced clinical programs for hospital, hospice and home-based end-of-life care, and funding aligned with these mandates, as well as earlier and ongoing palliative care education are needed. More clinical and health services research will help to identify innovative, feasible, cost-effective strategies to optimize the dying experience. Sharing of existing successful local, provincial and national strategies could also help to advance the cause.<sup>9</sup> Although personalized, compassionate and culturally sensitive end-of-life care may be a right

of every Canadian,<sup>10</sup> making it a reality requires more intense efforts by citizens, patients, providers and policy-makers working in concert toward this laudable goal.

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