

Next frontier: How can modern medicine help dying patients achieve a 'good' death?

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"Fear of dying is something almost every patient with advanced cancer or other life-threatening illness faces, and helping them, to achieve a 'good death' is an important goal of palliative care," said Dr. Sarah Hales. Credit: Dr. Sarah Hales

The overall quality of death of cancer patients who die in an urban Canadian setting with ready access to palliative care was found to be good to excellent in the large majority of cases, helping to dispel the myth that marked suffering at the end of life is inevitable.

"Fear of dying is something almost every patient with [advanced cancer](#) or other life-threatening illness faces, and helping them, to achieve a "good death" is an important goal of [palliative care](#)," says Dr. Sarah Hales, Coordinator of Psychiatry Services, Psychosocial Oncology & Palliative Care, Princess Margaret Cancer Centre. "We know a lot about disease and the physical symptoms that it may produce, but only recently have we focused on approaches to relieve the fear of death in patients and families and to address the emotional, spiritual and existential concerns that support the quality of the dying experience."

Understanding the multiple dimensions of the dying process has helped us better care for patients and families at this stage of life, says Dr. Rodin, Head of the Department of Psychosocial Oncology and Palliative Care at the Princess Margaret Cancer Centre. "We have found that individuals evaluate differently the dimensions of the experience, which include symptom control, the sense of life closure and facing the end of life without overwhelming fear. The perspectives of patients on these issues at the end of life may differ from those of their family and health care providers."

The study, entitled "The Quality of Dying and Death in Cancer and Its Relationship to Palliative Care and Place of Death," is in press but on-line in the prestigious *Journal of Pain and Symptom Management*, with Dr. Sarah Hales, Lecturer, Department of Psychiatry, University of Toronto as lead author, as well as Drs. Camilla Zimmerman, Head of Palliative Care at the Princess Margaret, and Gary Rodin, Professor of Psychiatry at the University of Toronto and Academic Director of the Kensington Hospice.

Thirty-nine percent (39%) of the sample scored in the "good" to "almost perfect" range of a scale measuring the dying experience, with 61% of the sample scoring in the "neither good nor bad" range of the scale. Better scores were linked to older patients, high social support (most patients were not living alone), older caregiver age, English as the primary language of the caregiver, greater length of relationship between the caregiver and patient, less caregiver bereavement distress (i.e. grief, stress-response, and depressive symptoms) and home death.

The study examined 402 deaths of [cancer patients](#) between 2005 and 2010 in the three acute care hospitals of University Health Network and from the Tammy Latner Centre for Palliative Care, a home palliative care program at Mount Sinai Hospital in Toronto. Caregivers of the patients who spoke and

read English were contacted and, those who agreed, were interviewed about the quality of death and dying using the Quality of Dying and Death (QODD) questionnaire, the most widely used and best validated tool to assess the dying experience.

The questionnaire includes 31 items covering symptoms and personal care, treatment preferences, time with family, whole person concerns, preparation for death, and the moment of death, with special attention to four key domains: Symptom Control, Preparation (i.e. visiting with spiritual advisor, avoiding life support, having funeral arrangements in order), Connectedness (i.e. spending time with family and friends), Transcendence (i.e. feeling unafraid of dying, feeling at peace with dying, feeling untroubled about strain on loved one). A total score on all variables was calculated from 0 to 100.

About one-third of all the cancer deaths occurred at home, while 40% occurred in an inpatient hospice/palliative care unit and 28% in an acute care hospital.

Receiving late or no palliative care was most common amongst those dying in a hospital, followed by those dying in a hospice/palliative care unit and least common amongst those dying at home. A late or no referral did not contribute to a worse overall quality of dying and death, but the authors state that this may mean that oncologists and family physicians provide good end-of-life care and that those who have more complicated illnesses are more likely to be referred to palliative care.

Home deaths were linked to better overall scores on the death experience, along with better Symptom Control and Preparation scores than dying in an acute-care or hospice setting. Surprisingly, home death with briefer palliative care was linked to better preparation and overall quality of dying than home death with longer palliative care involvement (i.e. greater than seven days).

In another surprise finding, there was no significant difference between a death in a hospice or palliative care setting and an acute care hospital. "You can have a good death in a hospice or a

hospital setting when there is high quality palliative care," says Dr. Hales. "Caregivers often feel incredibly guilty about their loved ones dying in hospital, but it may not always be possible to die at home. Complicated symptoms, lack of advanced care planning and caregivers who feel overwhelmed with the process could indicate that a hospice or hospital death might be better for the patient and the family."

Although the dying and death experience ratings were generally positive, for a substantial minority, symptom control and [death](#)-related distress at the end of life were problematic. Fifteen per cent (15%) of the sample scored in the "terrible" to "poor" range for symptom control, with 19 percent scoring in the same range for Transcendence – feeling unafraid of or making peace with dying. These could be areas in which further interventions are needed to improve outcomes, say the authors.

Provided by University Health Network

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