Original Article

The Quality of Dying and Death in Cancer and Its Relationship to Palliative Care and Place of Death

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Abstract

Context. Health care is increasingly focused on end-of-life care outcomes, but relatively little attention has been paid to how the dying experience is subjectively evaluated by those involved in the process.

Objectives. To assess the quality of death of patients with cancer and examine its relationship to receipt of specialized palliative care and place of death.

Methods. A total of 402 deaths of cancer patients treated at a university-affiliated hospital and home palliative care program in downtown Toronto, Ontario, Canada were evaluated by bereaved caregivers eight to 10 months after patient death with the Quality of Dying and Death (QODD) questionnaire. Caregivers also reported on bereavement distress, palliative care services received, and place of death.

Results. Overall quality of death was rated "good" to "almost perfect" by 39% and "neither good nor bad" by 61% of caregivers. The lowest QODD subscale scores assessed symptom control (rated "terrible" to "poor" by 15% of caregivers) and transcendence over death-related concerns (rated "terrible" to "poor" by 19% of caregivers). Multivariable analyses revealed that late or no specialized palliative care was associated with worse death preparation, and home deaths were associated with better symptom control, death preparation, and overall quality of death.

Preliminary study findings were presented in part at the following academic conferences: International Congress on Palliative Care, Montreal, Canada, September 2008; World Congress of Psycho-Oncology, Quebec City, Canada, May 2010; and Toronto Cancer Conference, Toronto, Canada, October 2011.

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Conclusion. The overall quality of death was rated positively for the majority of these cancer patients. Ratings were highest for home deaths perhaps because they are associated with fewer complications and/or a more extensive support network. For a substantial minority, symptom control and death-related distress at the end of life were problematic, highlighting areas for intervention. J Pain Symptom Manage 2014;48:839—851. © *2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Quality of dying and death, good death, palliative care, place of death, cancer, bereavement, caregivers

Introduction

Despite advances in treatment, cancer remains a leading cause of death worldwide, accounting for 8.2 million deaths in 2012.[1] Although large studies in Canada and the United States have characterized the end-of-life experience in terms of numbers of symptoms, location, and aggressiveness of care,[2,3] there has been comparatively little study of the dying and death experience from the perspective of the patients and families involved in the process.[4,5]

The quality of dying and death refers to the evaluation of the dying experience as a whole, according to one's expectations and values.[6] This construct, which includes subjective evaluations of the physical and psychological experiences, life closure and death preparation, the nature of health care, and the circumstances of death, is distinct from related constructs of quality of life and quality of care at the end of life.[7] Validated measures of the quality of dying and death have been developed,[8] and their application in advanced cancer populations may serve to enhance our understanding of the end stages of this illness. Many of these measures rely on the retrospective report of bereaved caregivers whose perspectives are important in their own right, given that they are co-recipients of palliative and end-of-life care, are treatment decision makers when patients are incapable, and may suffer from grief and bereavement-related distress long after patients have died.

Health care delivery factors, including specialized palliative care and the location of end-of-life care, may influence the quality of dying and death. Early involvement of specialized palliative care services has been associated with better quality of life for patients with cancer,[9,10] less frequent use of chemotherapy in the last 60 days of life, and greater enrollment in hospice care.[11] Evidence also suggests that death at home, where the majority of patients prefer to die,[12] where better quality of life can be maintained,[13] or in a hospice/palliative care unit where the dying process is normalized, and where there is a focus on symptom management,[14] may be associated with better evaluations of the dying experience than death in an acute care hospital.

The objectives of the present study were to explore the quality of dying and death of a sample of advanced cancer patients in an urban Canadian setting and examine the relationship of the quality of dying and death to length of specialized palliative care received and to place of death. We hypothesized that poorer quality of dying and death would be associated with receipt of late or no specialized palliative care and with death in an acute care hospital setting.

Methods

Protocol and Recruitment

Deaths of patients with metastatic cancer who received health care in downtown Toronto, Ontario, Canada, were identified in one of three ways: 1) by prospective tracking of deaths, between September 2005 and June 2010, of patients enrolled in an observational study of distress and quality of life at The Princess Margaret Cancer Centre, University Health Network (UHN) in Toronto (study findings published elsewhere[15]); 2) from retrospective lists of patients who died between February and September 2009 while receiving care from the Temmy Latner Centre for Palliative Care, a home palliative care program