

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 elsewhere¹⁵); 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

affiliated with Mount Sinai Hospital in Toronto; and 3) from retrospective lists of patients who died between July 2009 and July 2010 in one of the three UHN hospitals (The Princess Margaret, Toronto General Hospital, and Toronto Western Hospital). These three subsamples were pooled to examine a larger number of cancer deaths in an urban setting where inpatient, outpatient, and home-based palliative care services were available through universally funded provincial health insurance. Study inclusion criteria were as follows: a patient diagnosis of metastatic cancer and age more than 18 years, and available contact information for the caregiver (identified by the patient before death or listed as next-of-kin in their medical chart).

Six months after patient death, bereaved caregivers were contacted regarding participation in this study. An initial letter was sent informing them about the study and that they would receive a follow-up telephone call to discuss participation in more detail. If unreachable by telephone, repeat calls at different times of day were made and up to two voice mail messages were left inviting caregivers to contact the research team. Caregivers were excluded if they were younger than 18 years of age, unable to speak or read English sufficiently to complete questionnaires, or were not with the patient during the last week of life. In-person or telephone interviews were scheduled for eight to 10 months after patient death. The protocol was approved by the UHN Research Ethics Board, and all participants provided informed consent.

A total of 1457 cancer patient deaths meeting eligibility criteria were identified; 406 (30%) caregivers were unreachable by mail and/or telephone, and 135 (9%) were excluded because of caregiver ineligibility (i.e., language barrier or insufficient knowledge of patient's death). Of the 916 eligible caregivers reached, 457 (49.9%) consented to participate and 459 (50.1%) refused. Of the 457 who consented, 55 (12%) withdrew before completion of the interview. This analysis is therefore based on a total of 402 patient deaths.

Measures

Patient variables (age, gender, cancer type, and illness length) were obtained via medical chart review. Caregiver variables (age, gender,

place of birth, primary language, education, and the nature and length of the patient/caregiver relationship) and end-of-life care variables (duration of specialized palliative care received and place of death) were obtained via caregiver report. Patient and caregiver postal codes were used to estimate household income based on 2001 Statistics Canada census data. For the purpose of this analysis, late referral to palliative care was defined as within the last week of life.¹⁶

Caregiver bereavement distress was measured with The Texas Revised Inventory of Grief Part II¹⁷ to assess present grief symptoms, the Impact of Event Scale-Revised¹⁸ to assess stress-response symptoms, and the Beck Depression Inventory II¹⁹ to assess depressive symptoms.

The quality of dying and death was measured with the Quality of Dying and Death (QODD) questionnaire,²⁰ the most widely used and best validated instrument to assess the quality of dying and death.⁸ This interview includes 31 items covering symptoms and personal care, treatment preferences, time with family, whole person concerns, preparation for death, and the moment of death. For each item, a quality score is obtained by asking respondents, "How would you rate this aspect of the patient's dying experience?" on a scale from 0 to 10 (0 representing a "terrible" experience and 10 representing an "almost perfect" experience). These 31 quality scores are averaged and multiplied by 10 to generate a QODD total score on a scale from 0 to 100. The QODD developers have suggested²¹ that attention be focused on four latent variables (based on 17 items reported to be medium and high end-of-life priorities): symptom control (i.e., pain control, control over what was going on, ability to breathe comfortably), preparation (i.e., having means to hasten death if desired, visiting with spiritual advisor, having funeral arrangements in order, avoiding life support, having health care costs covered), connectedness (i.e., sharing physical expressions of affection, spending time with family and friends), and transcendence (i.e., feeling unafraid of dying, feeling at peace with dying, feeling untroubled about strain on loved ones).

Analysis

Descriptive statistics were calculated for all variables. Patient and caregiver incomes were

log transformed to stabilize the variance. Associations between variables and study subsamples were examined using a nonparametric version of the one-way analysis of variance known as the Kruskal-Wallis test for continuous variables and, for categorical variables, a Fisher's exact test or Chi-squared test where the Fisher's exact test failed. Univariate associations between each variable and receipt of less than one week of specialized palliative care and place of death were examined using the Kruskal-Wallis test for continuous variables and, for categorical variables, a Fisher's exact test or Chi-squared test where the Fisher's exact test failed. Univariate associations between variables and the quality of death were modeled using simple linear regression. Multivariable linear regression was used to examine the simultaneous influence of multiple predictors on quality of dying and death scores. For each model, receipt of less than one week of specialized palliative care, place of death, a statistical interaction between place of death and receipt of palliative care, and those potentially confounding variables associated with both independent and dependent variables ($P < 0.10$) were entered and retained if significant ($P < 0.05$) while controlling for other confounders. Place of death was dichotomized in the final models to home death vs. non-home death. The final reported multivariable analyses were modeled using linear mixed-effect models with study subsample as a random effect. The normality assumption was assessed through the use of Q-Q plots and the homogenous variability assumption through residual plots. The statistical software R version 3.0.1 was used for all analyses.

Results

Sample Characteristics

Table 1 summarizes patient and caregiver demographics, illness, and care variables. Characteristics are listed for the full sample and the three subsamples. The mean age of the patients at death was 66.9 (standard deviation [SD], 14.2) years, with a range from 24 to 97 years. The caregiver mean age was lower, at 56.8 (SD, 13.0) years. Only 13% of the patients lived alone. Both patients and caregivers were relatively affluent, with a mean yearly household income of \$99,980 and \$97,540,

respectively. The caregiver sample was primarily English speaking (89%), Canadian born (70%), and well educated with 74% having some post-secondary education. Regarding bereavement distress, mean levels of caregiver grief, stress-response symptoms, and depressive symptoms were in the low to moderate range. Several variables (i.e., patient age, whether the deceased lived alone, cancer site, time from diagnosis to death, caregiver age, caregiver education, relationship to patient, years known, grief symptoms, stress-response symptoms, depressive symptoms, place of death, and receipt of specialized palliative care) were found to have a significant relationship with study subsample indicating that there were differences between the three subsamples.

Receipt of Specialized Palliative Care

Of the total sample, 73 patients (18%) received no specialized palliative care before death. Of the 329 patients who received specialized palliative care, 41 (13%) received it for less than seven days before the end of life. Table 2 summarizes sample characteristics with a significant relationship to receipt of palliative care. Receipt of late or no palliative care (i.e., zero to six days) was associated with less time from diagnosis to death and non-home death ($P < 0.05$).

Place of Death

Of the total sample, 130 (32%) patients died at home, 152 (38%) in an inpatient hospice/palliative care unit, 9 (2%) in a long-term care facility, and 111 (28%) in an acute care hospital setting. Given the small number of long-term care facility deaths, these were combined with inpatient hospice/palliative care unit deaths in further analyses. Table 2 summarizes the relationship of sample characteristics to place of death. Place of death was associated with patient age, time from diagnosis to death, type of cancer, caregiver stress-response symptoms, and receipt of late or no palliative care ($P < 0.05$). Receipt of late or no palliative care was most common among those dying in hospital followed by those dying in hospice/palliative care unit/care facility and least common among those dying at home.

Table 1
Sample Characteristics by Full Sample and Study Subsample

Characteristic	Full Sample (<i>n</i> = 402 ^a)	Subsample 1: Oncology Clinic Outpatients (<i>n</i> = 137)	Subsample 2: Home Palliative Care Program (<i>n</i> = 146)	Subsample 3: Hospital Inpatients (<i>n</i> = 119)	<i>P</i> -value ^b
Patient age at death in years					
Mean (SD)	66.9 (14.2)	63.5 (11.4)	73.3 (13.8)	63.2 (15.0)	<0.001
Patient gender					
Female	192 (48)	62 (45)	77 (53)	53 (45)	0.32
Male	210 (52)	75 (55)	69 (47)	66 (55)	
Patient lived alone					
Yes	54 (13)	0 (0)	40 (27)	14 (12)	<0.001
No	321 (80)	111 (81)	106 (73)	104 (87)	
Unknown	27 (7)	26 (19)	0 (0)	1 (1)	
Patient yearly household income in dollars					
Mean (SD)	98,980 (72,664)	94,380 (62,304)	106,200 (92,049)	95,460 (54,373)	0.07
Cancer site					
Gastrointestinal	285 (71)	80 (58)	118 (81)	87 (73)	<0.001
Lung	65 (16)	38 (28)	22 (15)	5 (4)	
Other	52 (13)	19 (14)	6 (4)	27 (23)	
Time from diagnosis to death in months					
Mean (SD)	42.0 (59.1)	39.8 (39.8)	54.4 (80.5)	29.3 (42)	<0.001
Caregiver age in years					
Mean (SD)	56.8 (13)	59.2 (12)	55.5 (13)	55.9 (14)	0.01
Caregiver gender					
Female	286 (71)	102 (74)	103 (71)	81 (68)	0.51
Male	116 (29)	35 (26)	43 (29)	38 (32)	
Caregiver yearly household income in dollars					
Mean (SD)	97,540 (64,183)	90,370 (48,555)	99,800 (73,482)	103,000 (67,458)	0.20
Caregiver country of birth					
Canada	281 (70)	93 (68)	104 (71)	84 (71)	0.83
Other	121 (30)	44 (32)	42 (29)	35 (29)	
Caregiver primary language					
English	357 (89)	116 (85)	134 (92)	107 (90)	0.16
Other	45 (11)	21 (15)	12 (8)	12 (10)	
Caregiver education					
High school or less	104 (26)	35 (26)	29 (20)	40 (34)	0.041
More than high school	298 (74)	102 (74)	117 (80)	79 (66)	
Lived with patient					
Yes	268 (67)	111 (81)	73 (50)	84 (71)	<0.001
No	134 (33)	26 (19)	73 (50)	35 (29)	
Relationship to patient					
Spouse/common law	219 (54)	98 (72)	51 (35)	70 (59)	<0.001
Parent	12 (3)	6 (4)	1 (1)	5 (4)	
Son/daughter	127 (32)	21 (15)	77 (53)	29 (24)	
Sibling	18 (4)	4 (3)	7 (5)	7 (6)	
Other family	11 (3)	4 (3)	4 (3)	3 (3)	
Friend	15 (4)	4 (3)	6 (4)	5 (4)	
Length of relationship to patient in years					
Mean (SD)	40.4 (14.4)	48.6 (12.9)	44.6 (14.5)	37.3 (15)	<0.001
TRIG (13–65)					
Mean (SD)	43.4 (10.9)	44.2 (9.8)	40.4 (11.7)	46.0 (10.4)	<0.001
IES-R (0–4)					
Mean (SD)	1.1 (0.7)	1.0 (0.6)	1.0 (0.8)	1.3 (0.7)	<0.001
BDI-II (0–63)					
Mean (SD)	9.9 (8.3)	8.8 (7.4)	9.3 (8.3)	11.8 (8.9)	0.009
Received specialized palliative care					
No—0 days	73 (18)	20 (15)	9 (6)	44 (37)	<0.001
Yes—1–6 days	41 (10)	15 (11)	6 (4)	23 (19)	
Yes—More than 7 days	288 (72)	102 (74)	134 (92)	52 (44)	
If received specialized palliative care, number of days					
Mean (SD)	116 (193)	118 (205)	143 (208)	62 (122)	<0.001
Place of death					
Home	130 (32)	51 (37)	79 (54)	0 (0)	<0.001
Hospice/palliative care unit	152 (38)	55 (40)	34 (23)	63 (53)	

(Continued)

Table 1
Continued

Characteristic	Full Sample (<i>n</i> = 402 ^a)	Subsample 1: Oncology Clinic Outpatients (<i>n</i> = 137)	Subsample 2: Home Palliative Care Program (<i>n</i> = 146)	Subsample 3: Hospital Inpatients (<i>n</i> = 119)	<i>P</i> -value ^b
Acute care hospital unit	111 (28)	28 (20)	27 (18)	56 (47)	
Other care facility	9 (2)	3 (2)	6 (4)	0 (0)	
Total QODD (0–100)					
Mean (SD)	65.3 (12.7)	66.8 (11.8)	65.5 (12.2)	63.3 (14.1)	0.14
Symptom control (QODD subscale, 0–100)					
Mean (SD)	54.4 (23.4)	56.8 (24.5)	54.3 (24.1)	51.9 (23.9)	0.28
Preparation (QODD subscale, 0–100)					
Mean (SD)	76.5 (15.0)	76.0 (13.2)	79.1 (14.8)	74.1 (6.6)	0.027
Connectedness (QODD subscale, 0–100)					
Mean (SD)	81.5 (15.8)	80.4 (16.7)	81.2 (14.7)	83.2 (16.0)	0.28
Transcendence (QODD subscale, 0–100)					
Mean (SD)	54.2 (26.3)	57.8 (24.5)	52.0 (26.8)	52.6 (27.4)	0.17

SD = standard deviation; TRIG = Texas Revised Inventory of Grief; IES-R = Impact of Event Scale-Revised; BDI-II = Beck Depression Inventory II; QODD = Quality of Dying and Death.

^aAll variables are *n* = 402 except patient age (*n* = 401), time from diagnosis to death (*n* = 399), length of relationship to patient (*n* = 401), TRIG (*n* = 382), IES-R (*n* = 382), and BDI-II (*n* = 382).

^b*P*-values refer to significance of Kruskal-Wallis test for continuous variables and Fisher's exact test or chi-square test for categorical variables. *P*-values below 0.05 are in bold.

Quality of Dying and Death

The mean total QODD score was 65.3 (SD, 12.7), with 39% of the sample scoring in the “good” to “almost perfect” range of the scale (i.e., 70–100) and 61% of the sample scoring in the “neither good nor bad” range of the scale (i.e., 30–69). The lowest subscale scores were for symptom control (mean, 54.4; SD, 23.3), with 15% of the sample scoring in the

“terrible” to “poor” range, and transcendence (mean, 54.2; SD, 26.3), with 19% of the sample scoring in the “terrible” to “poor” range. Figure 1 illustrates the proportion of subscale and total scores falling into the poor, intermediate, and good ranges of the scale.

Table 3 summarizes the relationship of sample characteristics to the quality of dying and death. Better total QODD scores were associated with

Table 2
Univariate Relationships Between Sample Characteristics and Receipt of ≥ 1 Week of Palliative Care and Place of Death (*n* = 402^a)

Characteristic ^b	Palliative Care Received			Place of Death			<i>P</i> -value ^c
	Median/ Proportion Receiving ≥1 Week	Median/ Proportion Receiving <1 Week	<i>P</i> -value ^c	Median/ Proportion Home Death	Median/ Proportion Acute Care Hospital Death	Median/Proportion Hospice/Palliative Care Unit/Care Facility Death	
Patient age at death in years	67.1	65.5	0.11	71.3	65.3	65.5	0.003
Cancer site (%)							
Gastrointestinal	70.9	29.1	0.36	33.3	28.4	38.2	0.020
Lung	78.5	21.5		41.5	18.5	40.0	
Other	67.3	32.7		15.4	34.6	50.0	
Time from diagnosis to death in months	23.6	18.0	0.002	24.8	16.7	20.1	0.003
IES-R (0–4)	0.90	1.02	0.16	0.76	1.02	1.01	0.002
Received specialized palliative care (%)							
<1 Week (0–6 days)				9.6	61.4	28.9	<0.001
≥1 Week (≥7 days)				41.3	14.2	44.4	

IES-R = Impact of Event Scale-Revised.

^aAll variables are *n* = 402 except: patient age (*n* = 401); time from diagnosis to death (*n* = 399); length of relationship to patient (*n* = 401); TRIG (*n* = 382); IES-R (*n* = 382); BDI-II (*n* = 382).

^bOnly characteristics with a significant relationship (*P* < 0.05) to either palliative care received or place of death are listed.

^c*P*-values refer to significance of Kruskal-Wallis test for continuous variables and Fisher's exact test for categorical variables. *P*-values below 0.05 are in bold.

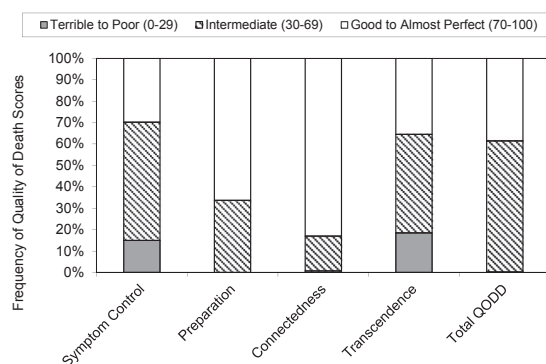


Fig. 1. QODD subscale and total QODD score frequencies. QODD = Quality of Dying and Death.

older patient age, older caregiver age, caregiver primary language English, greater length of relationship, less caregiver bereavement distress (i.e., grief, stress-response, and depressive symptoms), and home death ($P < 0.05$). Table 4 summarizes the final multivariable regression models predicting QODD total and subscale scores. As Figure 2 illustrates, controlling for confounding variables, late or no receipt of specialized palliative care was found to predict worse preparation but no other subscale scores nor the total QODD score ($P < 0.05$). As Figure 3 illustrates, when controlling for confounding variables, home deaths were associated with better total QODD scores, better symptom control, and better preparation subscale scores than hospice/palliative care unit/care facility or acute care hospital deaths ($P < 0.05$). There was no significant difference found between deaths in hospice/palliative care unit/care facility and acute care hospital. There was a significant interaction between place of death and receipt of palliative care found in models predicting both preparation and total QODD scores (i.e., the effect of home death was different depending on whether the patient received more or less palliative care)—surprisingly, home death with briefer palliative care was associated with better preparation and overall quality of dying and death than home death with longer palliative care involvement.

Discussion

This retrospective study pooled patient deaths from three subgroups (patients followed in oncology outpatient clinics, patients

cared for by a home palliative care program, and patients dying in one of three UHN hospitals) to examine the quality of dying and death of a larger sample of cancer patients cared for in an urban Canadian setting. The majority of quality of dying and death ratings were highly favorable with a substantial minority of negative ratings for subscales assessing symptom control and transcendence (15% and 19%, respectively). After controlling for potential confounding variables, the best overall quality of dying and death ratings were reported for deaths at home compared with non-home deaths with no significant difference between ratings of deaths in an inpatient hospice/palliative care unit/care facility and those in an acute care hospital.

Factors that might have contributed to these overall positive ratings included the availability of universally funded specialized palliative care in the study setting (downtown Toronto, Ontario, Canada), the relative affluence and education of the samples, and the presence of high social support (i.e., the majority of patients were not living alone). Bereavement distress was not high in these caregivers, perhaps because of the length of time since bereavement and the relatively high quality of the deaths. Nonetheless, fear of the dying process is common among those who face it,^{22,23} and these findings may correct some negative expectations and alleviate some of the anticipatory distress experienced by cancer patients and their families.

Our findings are consistent with other observations that a substantial minority of patients have distressing physical symptoms at the end of life.^{24,25} Less attention has been paid in previous research to the death-specific distress captured in the QODD transcendence subscale, which asks about fear of dying, peace with dying, and worry about strain on loved ones. Our results underscore the need for further research into death-related distress and interventions that can target this issue before the end of life.

Late or no referral to palliative care (i.e., six days or less of palliative care involvement) was associated only with poorer death preparation but, contrary to our hypothesis, not with worse overall quality of dying and death. This may indicate that excellent overall end-of-life care was provided by oncologists and/or family

Table 3

Univariate Relationships Between Sample Characteristics and Total Quality of Dying and Death ($n = 402^a$)

Characteristic	Estimate (95% CI)	P-value	Global P-value ^b
Patient age at death	0.11 (0.02 to 0.19)		0.016
Patient gender			0.10
Male	Reference		
Female	2.07 (−0.42 to 4.55)		
Patient lived alone			0.68
Yes	Reference		
No	−0.76 (−4.43 to 2.92)	0.69	
Unknown	1.36 (−4.53 to 7.24)	0.65	
Patient yearly household income	1.64 (−0.84 to 4.13)		0.20
Cancer site			0.40
Gastrointestinal	Reference		
Lung	1.91 (−1.52 to 5.34)	0.28	
Other	1.86 (−1.9 to 5.62)	0.33	
Time from diagnosis to death	0.01 (−0.01 to 0.03)		0.35
Caregiver age	0.2 (0.11 to 0.29)		< 0.001
Caregiver gender			0.35
Male	Reference		
Female	−1.3 (−4.04 to 1.44)		
Caregiver yearly household income	1.01 (−5.07 to 7.09)		0.74
Caregiver country of birth			0.92
Canada	Reference		
Other	−1.3 (−4.04 to 1.44)		
Caregiver primary language			0.025
Other	Reference		
English	4.49 (0.57 to 8.42)		
Caregiver education			0.36
High school or less	Reference		
More than high school	−1.33 (−4.17 to 1.51)		
Lived with patient			0.69
No	Reference		
Yes	0.53 (−2.11 to 3.17)		
Relationship to patient			0.59
Spouse/common law	Reference		
Parent	4.88 (−2.53 to 12.28)	0.20	
Son/daughter	−1.00 (−3.79 to 1.78)	0.48	
Sibling	2.25 (−3.88 to 8.37)	0.47	
Other family	2.72 (−5.00 to 10.43)	0.49	
Friend	1.07 (−5.59 to 7.74)	0.75	
Length of relationship to patient	0.14 (0.06 to 0.23)		0.001
TRIG	−0.2 (−0.32 to −0.08)		< 0.001
IES-R	−3.96 (−5.71 to −2.22)		< 0.001
BDI-II	−0.36 (−0.51 to −0.21)		< 0.001
Received specialized palliative care			0.14
No	Reference		
Yes	2.45 (−0.77 to 5.67)		
If received specialized palliative care, number of days	0 (−0.01 to 0.01)		0.78
Received specialized palliative care			0.10
<1 Week (0–6 days)	Reference		
≥1 Week (≥7 days)	2.33 (−0.42 to 5.08)		
Place of death			< 0.001
Home	Reference		
Hospice/palliative care unit	−4.32 (−7.25 to −1.40)	< 0.001	
Acute care hospital unit	−6.50 (−9.67 to −3.34)	0.004	
Other care facility	−0.32 (−8.76 to 8.11)	0.94	

CI = confidence interval; TRIG = Texas Revised Inventory of Grief; IES-R = Impact of Event Scale-Revised; BDI-II = Beck Depression Inventory-II.

^aAll variables are $n = 402$ except patient age ($n = 401$), time from diagnosis to death ($n = 399$), length of relationship to patient ($n = 401$), TRIG ($n = 382$), IES-R ($n = 382$), and BDI-II ($n = 382$).

^bP-values refer to significance of linear regression model predicting quality of dying and death. P-values below 0.05 are in bold.

doctors without referral to a designated palliative care service. It may also be that those with more distress and/or more complicated disease, who were perhaps more likely to have worse subjective outcomes, were more likely

to be referred to palliative care. This is supported by the finding that those dying at home with less palliative care involvement had better deaths than those dying at home with a longer duration of palliative care.

Table 4
Multivariable Analyses Predicting Quality of Dying and Death Subscale and Total Scores

Dependent Variable	Independent Variable	Estimate (95% CI)	P-value ^a	Global P-value ^a
Symptom control subscale ^b	Palliative care	Reference		0.64
	<1 week	1.26 (−4.02 to 6.54)		
	≥1 week			
	Home death	Reference		0.036
	No	5.51 (0.35 to 10.67)		
Preparation subscale ^c	Caregiver age	0.30 (0.13 to 0.48)		<0.001
	IES-R	−6.29 (−9.51 to −3.07)		<0.001
	IES-R	−2.73 (−4.80 to −0.67)		0.01
	Interaction between home death and palliative care			0.003
	Home death with <1 week	15.28 (5.80 to 24.75)	0.002	
Connectedness subscale ^d	Home death with ≥1 week	5.89 (1.83 to 9.95)	0.005	
	Palliative care	Reference		0.86
	<1 week	−0.33 (−3.96 to −3.30)		
	≥1 week			
	Home death	Reference		0.57
Transcendence subscale ^e	No	−1.02 (−4.50 to 2.47)		
	Yes			
	Palliative care	Reference		0.96
	<1 week	0.15 (−5.99 to 6.29)		
	≥1 week			
Total QODD ^f	Home death	Reference		0.25
	No	3.56 (−2.49 to 9.61)		
	Yes	0.43 (0.23 to 0.63)		<0.001
	Caregiver age	−4.82 (−8.2 to −1.11)		0.011
	IES-R	0.17 (0.08 to 0.26)		<0.001
	IES-R	−3.44 (−5.15 to −1.73)		<0.001
	Interaction between home death and palliative care			0.003
	Home death with <1 week	14.86 (7.03 to 22.70)	<0.001	
	Home death with ≥1 week	4.66 (1.41 to 7.91)	0.005	

CI = confidence interval; IES-R = Impact of Event Scale-Revised; QODD = Quality of Dying and Death.

^aP-values below 0.05 are in bold.

^bVariables discarded from the final regression model: patient age and length of relationship with patient.

^cVariables discarded from the final regression model: patient age, caregiver age, and length of relationship with patient.

^dVariables discarded from the final regression model: caregiver primary language.

^eVariables discarded from the final regression model: patient age, patient yearly income, caregiver primary language, and length of relationship with patient.

^fVariables discarded from the final regression model: patient age, caregiver primary language, and length of relationship with patient.

Previous research has emphasized that patients and families prefer death at home,¹² but large studies in Ontario, North America, and Europe^{26–30} have reported 30%–85% of cancer deaths occur in hospitals, depending on study setting. Despite the fact that in our study setting of urban Toronto, there is availability of universally funded home-based palliative care, approximately one-third of these cancer deaths examined occurred at home, whereas 40% occurred in an inpatient hospice/palliative care unit/care facility and 28% in an acute care hospital. Even for those patients followed by the home palliative care program, only 54% died at home. Home death in our study was associated with better overall quality of dying and death and better symptom

control and death preparation than non-home death, and there was no significant difference between death in an acute care hospital and death in an inpatient hospice/palliative care unit/care facility. Even in an “ideal” environment where funding and availability of home-based palliative care services would allow individuals with cancer the opportunity to die where they wish, those with difficult symptoms and without advance care planning might continue to die in institutional settings. Both cancer patients and families may benefit from the knowledge that, if not manageable at home, deaths in other locations can still be of good quality.

This study has several limitations. Three subsamples were pooled to create a larger

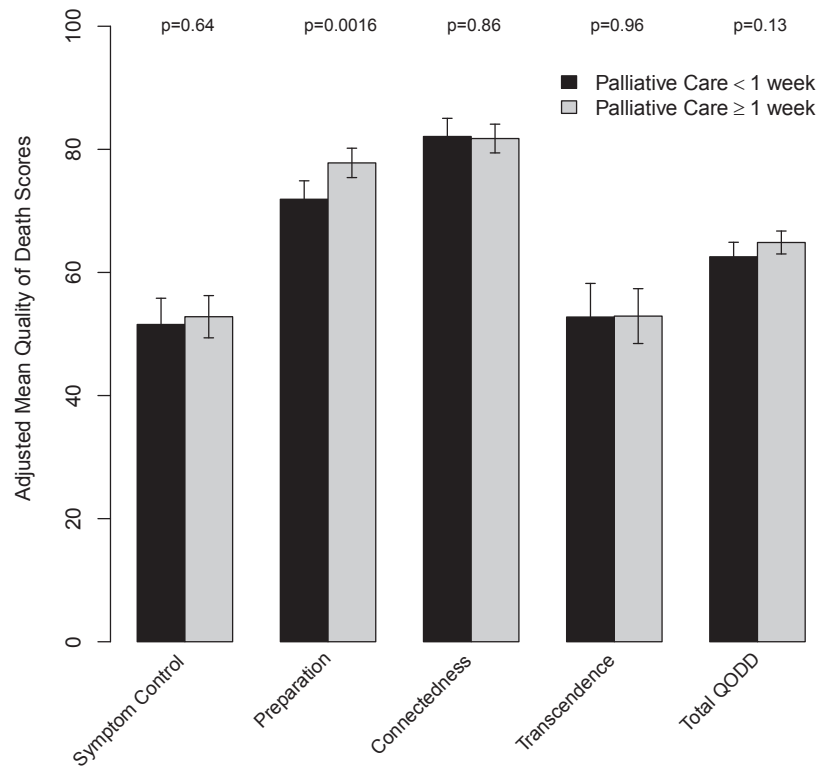


Fig. 2. Effect of receipt of a week or more of specialized palliative care, controlling for confounding variables, on QODD subscales and total QODD scores. Means are adjusted for confounding variables identified in regression analyses. Error bars represent 95% confidence intervals. QODD = Quality of Dying and Death.

sample of cancer patient deaths. Given this methodology, it is difficult to extrapolate these findings to a single broader population, and therefore, we have attempted to emphasize associations among variables which could serve as the basis for further research. A barrier to recruitment was the ability to reach caregivers via telephone to invite their participation. Of those caregivers reached, 49.9% consented. It is possible that in some cases, unanswered telephone calls and voice mail messages were passive expressions of lack of interest in this study. The overall recruitment rate of 30% is not inconsistent with that of other studies relying on similar methodology. In our review of the quality of dying and death measurement literature,⁸ in those studies that reported recruitment data, the proportion of family members approached who consented to these studies ranged from 27% to 57%. There are likely numerous factors involved in refusal, not the least of which are the anticipation of distress during the process of recounting details of their loved one's death

and reluctance to revisit painful memories. This is an important and yet perhaps unavoidable potential recruitment bias in research reliant on bereaved caregiver report. In addition to the low recruitment rate, the relatively urban, affluent, and Canadian born/nonimmigrant nature of the sample may limit generalizability of these findings. The cross-sectional design of the study does not allow causal interpretations of the data. Finally, the quality of dying and death was assessed via retrospective bereaved caregiver report eight to 10 months after patient death, and it is possible that the emotional state, perspective, recall ability of the caregiver, and the duration of time between the patient death and the data collection influenced the results,³¹ although retrospective examination of the very end of life is recognized as a necessary and valid methodology.³²

In conclusion, the overall positive findings regarding the quality of dying and death in these cancer patients with good access to palliative care may help to dispel myths that cancer

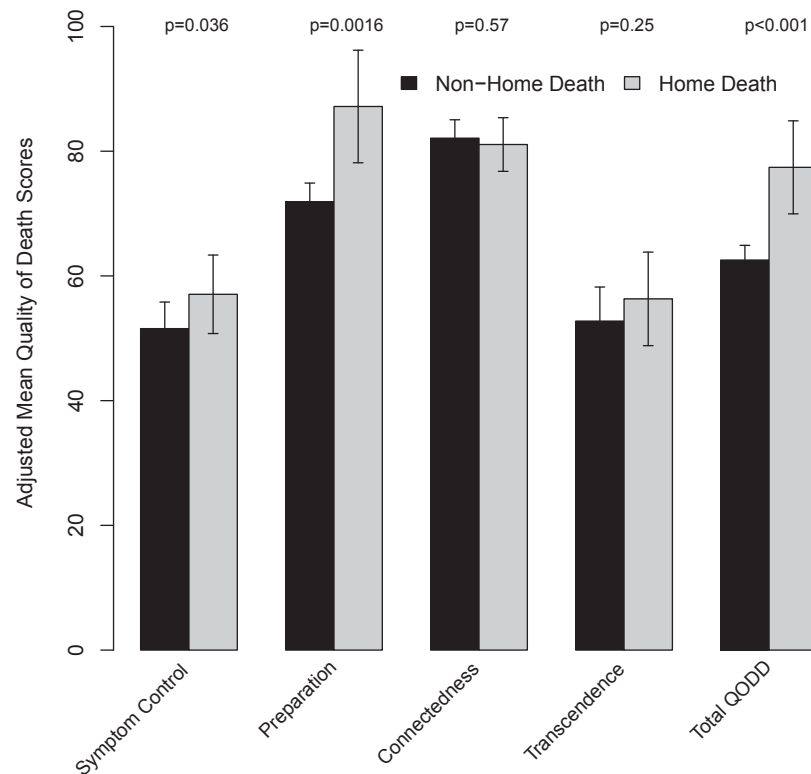


Fig. 3. Effect of home death, adjusting for confounding variables, on QODD subscales and total QODD scores. Means are adjusted for confounding variables identified in regression analyses. Error bars represent 95% confidence intervals. QODD = Quality of Dying and Death.

deaths are inevitably a negative experience. It is still of concern that in a substantial minority of these cases, symptom control and death-specific distress at the end of life were problematic. Further research is needed to understand better the factors that determine place of death, and how the nature of cancer care, the availability of palliative care services, and socioeconomic circumstances in other settings may affect the quality of dying and death.

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