

Quality of Death and Dying in Patients who Request Physician-Assisted Death

Kathryn A. Smith, M.S., PMHNP¹, Elizabeth R. Goy, Ph.D.,^{2,3}
Theresa A. Harvath, Ph.D., R.N., C.N.S., FAAN,¹ and Linda Ganzini, M.D., M.P.H.^{2,3}

Abstract

Background: Physician-assisted death (PAD) was legalized in 1997 by Oregon's Death with Dignity Act (ODDA). Through 2009, 460 Oregonians have died by lethal prescription under the ODDA.

Objective: To determine whether there was a difference in the quality of the dying experience, from the perspective of family members, between 52 Oregonians who received lethal prescriptions, 34 who requested but did not receive lethal prescriptions, and 63 who did not pursue PAD.

Design: Cross-sectional survey.

Measurements: Family members retrospectively rated the dying experience of their loved one with the 33 item Quality of Death and Dying Questionnaire (QODD).

Results: There were differences reported in 9 of the 33 quality item indicators. Few significant differences were noted in items that measured domains of connectedness, transcendence, and overall quality of death. Those receiving PAD prescriptions had higher quality ratings on items measuring symptom control (e.g., control over surroundings and control of bowels/bladder) and higher ratings on items related to preparedness for death (saying goodbye to loved ones, and possession of a means to end life if desired) than those who did not pursue PAD or, in some cases, those who requested but did not receive a lethal prescription.

Conclusions: The quality of death experienced by those who received lethal prescriptions is no worse than those not pursuing PAD, and in some areas it is rated by family members as better.

Introduction

IMPROVING END-OF-LIFE CARE is a priority for health care in the United States. Researchers are refining measurements of the end-of-life experience and factors associated with better quality of care and quality of death and dying. Quality of death and dying is comprised of a variety of elements including symptom management, treatment in accord with patient wishes, psychological health, spiritual and existential well-being, social support, and the experience of death.^{1,2}

Citizens in two states—Oregon (since 1997) and Washington (since 2009)—have legalized physician-assisted death (PAD) for terminally ill individuals. The Oregon Death with Dignity Act (ODDA)³ allows a patient to request a lethal dose of medication from a physician for the purposes of self-administration. Since passage in 1997, 460 Oregonians have died under the terms of the ODDA. Experts have speculated that patients may be motivated to pursue PAD to avoid poor quality of dying caused by

symptom distress and impaired physical function, psychological variables such as depression and hopelessness, lack of or conflicted social support, existential or spiritual distress, and perception of self as a burden.⁴⁻⁹ It has been suggested that improved end-of-life care could address these needs and thus alleviate the desire for PAD.^{4,8} Additionally, it has been postulated that presence of legal PAD might in fact result in a decline in the quality of end-of-life care for patients, as health care providers would prematurely consider PAD when faced with unmanaged symptoms¹⁰ or as a response to the burden of the cost of care.¹¹ In contrast to these concerns, previous research with patients and physicians, social workers and nurses, and family members involved with patients who chose PAD identified the importance of a desire to control circumstances of death, die at home, maintain independence and avoid future physical symptoms as possible contributors to requests for PAD.^{6,7,12,13} Whether access to a lethal prescription helps patients to meet these goals has not been investigated.

¹School of Nursing, ³Department of Psychiatry, Oregon Health & Science University, Portland, Oregon.

²Mental Health Division, Portland Veterans Affairs Medical Center, Portland, Oregon.

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In this study we investigate the quality of death and dying of terminally ill Oregonians as perceived by family members, and consider whether those who receive a lethal prescription under the ODDA encounter end of life experiences that differ objectively and subjectively from those who requested PAD but were unable to access it, and those who never requested PAD.

Methods

To understand the perceived differences in quality of death, we asked participants to evaluate the end-of-life experiences of their loved ones in terms of physical symptoms, preparation for death, existential transcendence, connections to others, and overall quality of life and death by using the Quality of Death and Dying (QODD), a validated instrument.¹⁴

Participants for this study were recruited from agencies and organizations in northwest Oregon willing to participate: two large medical centers, three large hospices, the Amyotrophic Lateral Sclerosis (ALS) Association of Oregon, and Compassion and Choices of Oregon. Compassion and Choices of Oregon is an advocacy organization that provides information, support and referral to those who qualify for assisted death under the ODDA. Four of these organizations kept registries of those pursuing PAD and made the initial contact with family members of decedents who made an explicit request for PAD to a physician (whether or not the patient received a prescription). After being notified of the opportunity, family members contacted the research team if they wished to participate. Compassion and Choices of Oregon identified 180 eligible primary informants, of whom 38% participated. Family members from other referral sources were a convenience sample. Potential participants were excluded if the loved one died less than 4 months or more than 3 years before the study or if the organization was not confident that the family member was aware of the request for PAD. Comparison family members were a convenience sample recruited from the hospices, medical centers, and the ALS Association noted above. The data were collected between 2004 and 2007 and conducted by study research personnel and Dr. Goy. Details of recruitment have been previously described.^{12,15}

This study was approved by the Institutional Review Board of the Portland Veterans Affairs Medical Center and the participating medical centers and hospices. All participants gave written informed consent to participate.

Measures

Quality of death and dying. The QODD is a retrospective, 33-item measure of the quality of dying and death for the time period immediately preceding the death from the perspective of family members.¹⁴ The interviewer-administered instrument elicits family rating of the frequency and quality of the patient's experiences during the last 7 days of life, or during the last 30 days of life if the loved one was unconscious or unresponsive during the last 7 days of life. The QODD assesses the domains of symptom control, social connectedness, preparation for death, and transcendence, with several items in each domain as indicators of quality. This instrument has evolved over time with use and subsequent validation. Recent factor analysis has led the instrument's authors to recommend a 17-item version with the four conceptual do-

main noted above¹⁶; however, our study was conducted before this recommendation and we used the original version of the instrument which includes items to rate global quality of death and the moment of death.

Indicators of quality (items) in each domain were evaluated by family members on two aspects: whether and with what frequency an indicator was present; and to what extent the presence or absence of that indicator affected their loved one's dying experience. Frequency ratings are either on a 6-point Likert scale (0 = none of the time; 5 = all of the time) or on a binary scale (yes/no) depending on the question. For example, family members are asked to rate "How often did (loved one's name) appear to be worried about strain on his/her loved ones?" or "Did (loved one) appear to find meaning and purpose in her/his life?" Family members are then asked to assess how this impacted quality with the question, "How would you rate this aspect of (loved one's name) dying experience?" on an 11-point Likert scale (0 = terrible experience; 10 = almost perfect experience). There are two global questions rating the quality of life in the last 7 days before death (or last 30 days under the conditions noted above) and at the moment of death on an 11-point Likert scale. Data from the 7-day and the 30-day versions of the QODD are combined.

Statistical analysis

Categorical data are presented as frequencies and proportions. Among the QODD continuous measures, many responses were not normally distributed. Because the sample size was large, $n = 147$, and each group size was relatively large ($n = 52, 32, \text{ and } 63$, respectively), it was possible that nonnormality and asymmetry would not affect the analysis. Therefore, we analyzed the data with parametric (analysis of covariance and Student's *t*-test) and non-parametric tests (Kruskal-Wallis) to assure the reliability of the results. In all but 5 cases the parametric and non-parametric results agreed; of those that differed, significance values were close and trended in expected directions. As such, we report continuous measures as means with standard deviations (SD) and compared the three groups with analysis of covariance. Family education level and whether or not the patient was enrolled in hospice were included as covariates in these analyses to account for group differences on these variables. If significant differences were found, *post hoc* analysis was conducted using a Bonferroni adjustment. We used χ^2 analysis to examine group differences on dichotomously scored variables. Because of the large number of comparisons that were not hypothesis-based, alpha was set at 0.01. Items with *p* values between 0.05 and 0.015 are identified as trending toward significance. Data analysis was completed with the Statistical Package for the Social Sciences (SPSS Inc., Chicago, IL) version 17.

Results

We surveyed 147 family members regarding their assessment of their loved one's dying experience, including 84 family members of patients who requested physician assisted death. The final data set included three groups of Oregonians: 52 decedents who requested and received a lethal prescription to facilitate assisted death (including 32 who died of PAD); 32 decedents who requested but did not receive the requested prescription; and 63 decedents who never pursued or re-

TABLE 1. CHARACTERISTICS OF FAMILY MEMBERS

Family member	Loved one requested and received PAD (n = 52)	Loved one requested but did not receive PAD (n = 32)	Comparison family member (n = 63)	p value
Relationship to patient, n (%)				NS ^{a,b}
Spouse/partner	33 (64)	17 (53)	37 (59)	
Daughter/son	15 (29)	9 (28)	17 (27)	
Other	4 (8)	6 (19)	9 (14)	
Gender, n (%) ^a				NS ^a
Male	17 (33)	10 (31)	13 (21)	
Female	35 (67)	22 (69)	50 (79)	
Family member ethnicity ^a				NS ^a
Caucasian	52 (100)	32 (100)	61 (97)	
Non-Caucasian	0 (0)	0 (0)	2 (3)	
Age (years), mean (SD) ^c	61.0 (13.3)	61.2 (12.2)	60.1 (14.2)	NS ^d
Educational achievement (years), mean (SD)	16.3 (3.4)	15.7 (2.3)	14.5 (3.2)	<0.05 ^d
How long known patient (years), mean (SD)	40.0 (16.1)	44.2 (15.3)	38.6 (16.6)	NS ^d
Days between death and interview, mean (SD)	396.4 (274.4)	453.4 (264.2)	446.8 (210.1)	NS ^d
Religiousness (mm) ^e	31.3 (37.9)	27.3 (35.7)	58.4 (38.3)	<0.001 ^d
Views on legalization of PAD ^f	1.1 (3)	1.1 (3)	2.4 (1.4)	<0.001 ^d

^a χ^2 test.

^bNS, not significant.

^cSD, standard deviation.

^dCompared with analysis of variance.

^e0–100 mm scale where 0 = religion not important to me, and 100 = religion very important to me.

^fFamily members' views on legalization of PAD; scale 1 = strongly support, 5 = strongly oppose.

PAD, physician-assisted death; SD, standard deviation.

requested a prescription to facilitate PAD (comparison group). Most family members were well-educated spouses or children, who had known the decedent for close to 40 years (Table 1). Ninety-nine percent of respondents were Caucasian. Family members of those who requested PAD were overall supportive of legalization of PAD and less religious than comparison family members. Most decedents were enrolled in hospice and died of cancer (Table 2).

Table 3 presents measures of frequency and impact that were statistically significant or trended toward significance.

Symptom control

Twelve items measured the severity of six symptoms and their impact on the quality of dying including pain; ability to feed self; control over surroundings and over bowel and

TABLE 2. CHARACTERISTICS OF DECEDENTS

Decedent	Loved one requested and received PAD (n = 52), n (%)	Loved one requested but did not receive PAD (n = 32), n (%)	Comparison decedent (n = 63), n (%)	p value
Gender				NS ^a
Male	32 (62)	16 (50)	36 (57)	
Female	20 (39)	16 (50)	27 (43)	
Hospice enrolled				<0.05
No	9 (17)	1 (3)	3 (5)	
Yes	43 (83)	30 (97)	60 (95)	
Terminal diagnosis				NS
Cancer	45 (87)	23 (72)	50 (79)	
ALS	3 (6)	1 (3)	6 (10)	
Other	4 (8)	8 (25)	7 (11)	
Place of death				NS
Home ^b	46 (90.2)	25 (80.6)	44 (69.8)	
Inpatient hospice	1 (2.0)	2 (6.5)	10 (15.9)	
Other	4 (7.8)	4 (12.9)	9 (14.3)	
QODD version				0.001
7 day	51 (98)	31 (97)	50 (79)	
30 day	1 (2)	1 (3)	13 (21)	

^aNS = not significant, all comparisons χ^2 test.

^bIncludes own home, surrogate home, and other home.

PAD, physician-assisted death; ALS, amyotrophic lateral sclerosis; QODD, Quality of Death and Dying Questionnaire.

TABLE 3. QUALITY OF DEATH AND DYING IN PATIENTS WHO REQUESTED AND DID NOT RECEIVE PHYSICIAN-ASSISTED DEATH

Item	Loved one requested and received PAD (1)	Loved one requested, but did not receive PAD (2)	Comparison decedent (3)	p value	Post hoc comparison
	N = 52	N = 32	N = 63		
Symptom control					
Control over surroundings, ^a mean (SD) ^b	3.8 (1.2)	2.6 (1.6)	2.3 (1.6)	0.000	1,2 $p < 0.01$ 1,3 $p < 0.001$
Control over surroundings, impact, ^c mean (SD)	7.6 (2.6)	6.0 (3.4)	5.5 (3.1)	0.006	1,3 $p < 0.01$
Ability to feed self, ^a mean (SD)	3.7 (1.8)	1.9 (1.9)	2.0 (1.9)	0.000	1,2 $p < 0.001$ 1,3 $p < 0.001$
Ability to feed self, impact, ^c mean (SD)	7.1 (2.8)	4.4 (3.1)	4.6 (3.0)	0.000	1,2 $p < 0.001$ 1,3 $p < 0.001$
Control bladder or bowels, ^a mean (SD)	3.1 (1.9)	1.8 (1.9)	2.2 (1.9)	0.008	1,2 $p < 0.05$
Control bladder or bowels, impact, ^c mean (SD)	6.0 (3.5)	3.8 (3.3)	4.7 (3.3)	0.015	1,2 $p < 0.05$
Energy to do things, ^a mean (SD)	1.1 (1.0)	0.6 (0.8)	0.8 (0.9)	0.011	1,2 $p < 0.05$
Energy to do things, impact, ^c mean (SD)	3.1 (2.6)	2.2 (2.3)	2.5 (2.6)	0.013	
Preparation					
Said goodbye to loved ones, ^d No. (%)	45 (87)	22 (69)	36 (57)	0.003	
Said goodbye to loved ones, impact, ^c mean (SD)	8.7 (2.3)	8.0 (2.4)	7.3 (2.9)	0.096	
Spiritual service before death, ^d No. (%)	4 (8)	6 (19)	22 (35)	0.002	
Spiritual service before death, impact, ^c mean (SD)	6.6 (2.1)	7.4 (2.3)	7.4 (2.4)	0.251	
Means to end life, ^d No. (%)	50 (96)	9 (28)	28 (44)	0.000	
Means to end life, impact, ^c mean (SD)	9.3 (1.9)	4.5 (3.6)	6.9 (2.3)	0.000	1,2 $p < 0.001$ 1,3 $p < 0.001$ 2,3 $p < 0.001$
Discussed end-of-life wishes, ^d No. (%)	49 (94)	29 (91)	54 (86)	0.342	
Discussed end-of-life wishes, impact, ^c mean (SD)	9.6 (0.9)	8.3 (2.7)	8.9 (1.6)	0.014	1,2 $p < 0.05$
Transcendence					
Worried about strain on loved ones ^a mean (SD)	2.8 (1.6)	1.9 (1.7)	2.4 (1.6)	0.033	1,2 $p < 0.05$
Worry strain on loved ones, impact, ^c mean (SD)	4.8 (2.9)	5.3 (3.0)	5.0 (2.6)	0.793	
Laugh and smile ^a mean (SD)	2.8 (1.2)	1.7 (1.2)	2.3 (1.3)	0.003	1,2 $p < 0.001$ 1,3 $p < 0.05$
Laugh and smile, impact, ^c mean (SD)	7.2 (2.7)	6.1 (2.9)	6.6 (2.9)	0.019	
Moment of Death					
Level consciousness at death ^c				0.012	
Awake	25 (48)	7 (22)	12 (19)		
Asleep	5 (10)	1 (3)	11 (17)		
Coma/unconscious	20 (38)	20 (63)	39 (62)		

^aScale 0 = none of the time, 5 = all of the time; compared with analysis of covariance; family education level and whether or not the patient was enrolled in hospice were included as covariates; post hoc comparison used a Bonferroni correction.

^bSD = standard deviation.

^cScale 0 = terrible experience, 10 = almost perfect; compared with analysis of covariance; family education level and whether or not the patient was enrolled in hospice were included as covariates; post hoc comparison used a Bonferroni correction.

^dYes/no scale, reported as percentage 'yes,' compared with Pearson's χ^2 missing data for these items range from 0% - < 10%.

PAD, physician-assisted death.

bladder; ability to breathe comfortably; and energy to do things. The three groups differed overall in control of surroundings, control of bladder and bowel, energy to do things, and ability to feed self, and *post hoc* analyses demonstrated that those who received a lethal prescription differed from the other two groups with better quality of dying related to control of surroundings and ability to feed self. Among those who requested PAD, those who received it had higher scores on control of bladder and bowel and energy to do things.

Connectedness

Indicators of connectedness were items measuring time spent with family and friends, attendance at important events, and physical expressions of affection. No items in the connectedness domain showed significant differences between the three groups.

Preparation

The domain preparation was measured by 18 items, including discussion of end of life wishes; clearing up bad feelings; use/avoidance of life support; having health care costs covered; visit from any religious advisor; spiritual service before death; having the means to end life if desired; funeral arrangements made; and goodbyes said.

Significant between-group differences were noted in having means to end life and discuss end-of-life wishes, spiritual services before death, and saying goodbye to loved ones. Those who received a lethal prescription were more likely to have said goodbye than those who did not pursue PAD, and were less likely to engage in a spiritual ceremony before death than those who did not pursue PAD.

Not surprisingly, the three groups differed on the item measuring possession of the means to end life if desired, and those who requested and received a lethal prescription were indeed more likely to be in possession of the means to end life than either those who requested but did not receive a lethal prescription or those who did not pursue PAD. Similarly, there were significant differences between all three groups in the family members' quality rating of the impact of possession of means to end life on the dying experience.

Transcendence

This domain included 12 items, including being unafraid of and at peace with dying; maintaining dignity; ability to laugh/smile; finding meaning in life; and worry about strain on loved ones. Significant between group differences were observed only in the item measuring ability to laugh/smile. Post hoc analysis revealed that those who received a lethal prescription were rated by family members as laughing/smiling more often in the final week of life than those decedents who requested a lethal prescription but did not receive it. There was a trend for those who requested but did not receive a lethal prescription to worry about their strain on loved ones.

Moment of death

Level of consciousness and presence of others was measured. There was a difference between the three groups in whether the loved one was awake, asleep, or in a coma in the moments before death.

Global ratings

Two items measured family members' perception of overall quality of death and dying: quality of life in the last 7 (or 30) days of life and quality of the moment of death. No differences between the groups were found on these items. In a separate analysis there was no difference in quality of life in the last 7 days of life for those who died by PAD (mean [SD] 4.1 [2.9]) versus those who received prescriptions but did not use them (mean [SD] 4.2 [2.6]). However, family members rated the quality of the moment of death as higher among those who took the prescription ($n = 32$; mean [SD] 9.6 [0.9]) compared to those who received a lethal prescription but did not take it ($N = 20$; mean [SD] 7.3 [3.2], $p < 0.001$).

Discussion

In this study we used the QODD to compare family perception of the quality of the dying experience between deceased Oregonians who pursued PAD and Oregonians who died of terminal illness without requesting PAD. We further distinguished between those who requested and received a lethal prescription for PAD and those who requested but did not receive the prescription. Domains evaluated by the instrument included symptom control, preparedness, connectedness, transcendence, and the moment of death. The main finding was that families perceived better quality of dying among patients who received lethal prescriptions when some physical symptoms were avoided and there was greater preparation for death.

Of the 33 different indicators of quality, significant between group differences were found in one or both aspects of 9 of the indicators. In domains of connectedness and transcendence there were very few differences between groups, and ratings of the moment of death and global ratings of quality of life did not differ, again indicating that those choosing PAD were similar to those not pursuing PAD in terms of quality of death.

In domains of symptom control and preparedness, however, significant differences were noted. Family members of those choosing PAD reported greater symptom control, particularly in regard to control over surroundings, better functioning, better energy, and better control of bowel and bladder. We previously found that at the time they expressed initial interest in PAD, Oregonians were motivated by worries about future discomfort, pain and other physical symptoms, but rated physical symptoms at the time of the request as relatively unimportant reasons for requesting a lethal prescription.⁶ Our data suggest that PAD may meet that goal in some patients if they are able to avoid symptoms that contribute to "states worse than death."¹⁷

Those choosing PAD were in some ways more prepared for death in that they were more likely to have said goodbye to loved ones, yet less likely to have had a spiritual service before death than those who did not. Previous studies have demonstrated that as the importance of religion increases, interest in PAD lessens. Furthermore, there was a trend toward significance in the positive impact of discussion of end of life wishes on the dying experience with those who received a lethal prescription reported by family members as finding greater positive effect of end-of-life discussions on the dying experience than those who did not pursue PAD.

One limitation of this study is that family members retrospectively assessed the quality of their loved one's dying

experience. It is unknown how closely family member assessment would correlate with the decedent's assessment. Research regarding the concordance of proxy respondents is mixed, with some authors reporting that proxy reporters are more accurate with observable indicators than with subjective indicators of quality¹⁸ and that proxies tend to report lower quality of life than patients report for themselves.¹⁹ However, given the frail nature of the patients and the potential burden of participating in end of life research, proxy respondents are viewed as an appropriate source of information on the final experiences of life.^{1,18} Additional limitations were the low participation proportion among the aid in dying families and the comparison family members were a convenience sample. It is unknown how non-response might be associated with the views on quality of death and dying.

A strength of this study was the use of the QODD, an instrument designed to specifically assess the end of life experience of terminally ill patients. Given the overlap of the concepts of quality of life at end of life, quality of death and dying, and quality of care at end of life, this instrument specifically assesses the quality of the dying experience and helps to elucidate the experience for those choosing PAD. PAD is a controversial issue that draws moral and ethical arguments both for and against the practice. This study does not address those arguments. However, another concern regarding the legalization of PAD is that PAD would become a substitute for quality end of life care. Our study does not support that the choice for PAD reflects poor symptom management.²⁰ In fact, in the view of family members it does appear to meet patients' preferences for control and avoidance of a period of declining function. Insofar as family rating of the quality of a loved one's death is an indicator of end of life care, this study adds to the evidence that the choice to pursue PAD does not appear to be due to, or a reflection of, poorer end of life care. Nor is the quality of death experienced by those choosing PAD any worse than for those not pursuing PAD; in some areas it is rated as better by family members.

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Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:

Linda Ganzini, M.D., M.P.H.

Mental Health Division

Portland Veterans Affairs Medical Center

3710 SW US Veterans Hospital Road

Portland, OR 97239

E-mail: Linda.Ganzini@va.gov