Original Article

A Measure of the Quality of Dying and Death: Initial Validation Using After-Death Interviews with Family Members

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Abstract

A reliable and valid measure of the quality of the dying experience would help clinicians and researchers improve care for dying patients. To describe the validity of an instrument assessing the quality of dying and death using the perspective of family members after death and to identify clinical correlates of a high quality death, a retrospective cohort study evaluated the 31-item Quality of Dying and Death (QODD) questionnaire. The questionnaire was administered to family members of patients who died in Missoula county Montana in 1996 and 1997. The interview included questions assessing symptoms, patient preferences, and satisfaction with care. Measurement validity was examined for item and total scores and reliability analyses for the QODD total score were assessed. Construct validity was assessed using measures of concepts hypothesized to be associated with the quality of dying and death. There were 935 deaths, of which 252 (27.0%) family interviews were represented. Non-enrolled decedents were not significantly different from enrolled decedents on age, sex, cause of death, or location of death. We excluded sudden deaths ($n = 45$) *and decedents under age 18* ($n = 2$)*, leaving 205 after-death interviews. A total QODD score, on a scale from 0 to 100 with higher scores indicating better quality, ranged from 26.0 to 99.6, with a mean of 67.4 and Cronbach's alpha of 0.89. The total QODD score was not associated with patient age, sex, education, marital status, or income. As hypothesized, higher QODD scores were significantly associated with death at home* ($P < 0.01$)*, death in the location the patient desired* ($P < 0.01$)*, lower symptom burden* ($P < 0.001$)*, and better ratings of symptom treatment* ($P < 0.01$)*. Although the total score was not associated with the presence of an advance directive, higher scores were associated with communication about treatment preferences* ($P < 0.01$)*, compliance with treatment preferences* ($P < 0.001$)*, and family satisfaction regarding communication with the health care team* ($P < 0.01$)*. Availability of a health care team member at night or on weekends was also associated with a higher QODD score* ($P < 0.001$)*. The QODD total score demonstrated good cross-sectional validity.*

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Clinicians caring for dying patients should focus on improving communication with the patient and family and improving symptom assessment and treatment. Health care teams should focus on continuity of care, including having a team member familiar with the patient available for calls at nights and on weekends. Future work will assess the potential role of the QODD in improving the quality of the dying experience. J Pain Symptom Manage 2002; 24:17–31. © *U.S. Cancer Pain Relief Committee, 2002.*

Key Words

Dying, death, palliative care, quality of life, outcome

Introduction

Improving the quality of health care for patients at the end of their lives has become a major national clinical and research objective.[1] Efforts to improve this care have included randomized, controlled trials of advance directives,[2,3] educational interventions,[4] and a comprehensive intervention that includes feedback of prognostic information to patients, families, and physicians and facilitation of physician–patient communication.[4] These interventions have not demonstrated any significant benefit. Part of the reason these interventions failed to improve quality of care may be due to the lack of sensitive measures of the outcomes that patients and families define as important.[5] Outcome measures that accurately assess these features of care at the end of life will allow us to identify, evaluate, and disseminate interventions that improve care at the end of life.

Using literature reviews and a series of qualitative studies, Patrick and Curtis have developed a measure of the "quality of dying and death" with the goal of measuring *the degree to which a person's preferences for dying and the moment of death are consistent with observations of how the person actually died as reported by others.*[6] Measuring the quality of dying and death according to this definition includes obtaining from patients their preferences about dying and death and comparing these preferences to reports from family members after death. In this article, we report on one component of this definition: after-death interviews with family members to elicit the families' perspectives of patients' experiences using a questionnaire titled "The Quality of Dying and Death" (QODD).

Much of the research on the quality of end-of-life care focuses on hospital care and care in academic institutions yet, although such institutions are important centers of research and education, a community-based approach incorporating deaths in diverse medical institutions as well as home settings would offer a more complete understanding of the range of end-of-life care and experience.[7,8] Studies of dying patients present methodologic and emotional challenges of prospectively identifying these patients and asking them to examine the dying process.[9] An after-death assessment, if valid, may offer the best opportunity to measure the quality of care during routine clinical care and provide the important measurement component of the continuous quality improvement cycle.[9] In this study, we use after-death interviews with the family members from a community-based sample of deaths to validate a measure of the quality of this experience and to examine the demographic and clinical correlates of the quality of dying and death.

Methods

Sample

Respondents were part of the Missoula Demonstration Project (MDP) in Missoula, Montana. MDP is a community-based research and community engagement organization whose mission is to improve quality at life's end in Missoula County. Using funeral records from the four funeral homes in Missoula County, we identified 1082 deaths occurring in the county in 1996 and 1997 and the primary and secondary contacts for each decedent. These years were chosen to precede interventions by MDP. A total of 147 deaths were excluded from the 1997 sample because they had been approached to participate in a pilot study testing study instruments, leaving 935 deaths eligible for this study. Primary contacts were sent a letter and then telephoned to ask if they, or one of the patient's other family members, would complete an in-person interview. If they consented over the telephone to participate in the study, an interview was scheduled and written informed consent was obtained prior to the interview. All interviews were conducted between 1 and 3 years after the death (mean = 708 days, range = 305–1035 days).

Of the 935 decedents' next of kin, 440 (47.1%) refused participation and 243 (26.0%) could not be reached due to an incorrect address or phone number. The following steps were taken to clarify poor addresses: 1) telephone directory review, 2) Polk Directory review, and 3) use of internet-based people search engines. When the primary contact listed in the funeral record could not be located, the secondary contact was invited to participate. The same process listed above was used to locate secondary contacts if their addresses were incomplete or if the letter was returned as undeliverable. Of those refusing to participate, 145 returned a refusal postcard giving no reason for refusal, and 261 refused by telephone. Reasons given during phone refusals included: "no reason given" (*n* = 196), "pain or grief" (*n* = 31), "too busy" (*n* = 20), and "too ill" (*n* = 14). An additional 34 respondents scheduled an interview, but did not make the appointment and could not be rescheduled.

The remaining 252 (27.0% of total sample; 36.4% of those contacted) family members consented to participate and completed an in-person interview. Because the questionnaire measures the experiences with dying and death over the last week or last month of life, we excluded 45 decedents who had a sudden and unexpected death. We also excluded 2 decedents who were less than 18 years old. These exclusions left 205 decedents who had a family member complete an in-person interview that included the QODD instrument. The 205 decedents were cared for by 79 different primary physicians (45 physicians were primary providers for 1 or 2 patients, 31 physicians for 3 to 12 patients, and 3 physicians for 13 or 14 patients.)

Measures

QODD. The development of the QODD has been described previously[6] and the individual items are listed in the Appendix. The QODD is an interviewer-administered questionnaire containing 31 items asking the respondent to rate the quality of the dying experience for the decedent's last seven days or, if the patient was unconscious or unresponsive during the last seven days, over the last month before death. The QODD items are rated on a scale from 0 (terrible experience) to 10 (almost perfect experience). Four items were dropped from this analysis because more than 50% of respondents answered "not applicable" (these four items were spending time with spouse, spending time with pets, clearing up bad feelings, and attending important events). A total score was calculated by adding the scores on the 27 remaining items and dividing this score by the number of items answered. This mean score was divided by the range of possible scores (10) and then multiplied by 100 to construct a scale ranging from 0 to 100, with higher scores indicating a better quality of dying and death. (We chose to use a total score for the QODD because preliminary factor analyses did not support subscale construction based on this relatively small sample. Further studies are underway to assess subscale construction.) Total QODD scores for respondents with five or fewer missing items were calculated by imputing the mean score for the missing items based on items completed by that individual. If there were more than 5 missing items (20%), a total score was not calculated for that individual. There were 23 respondents (11.2%) with questionnaires missing more than 5 items for which total scores were not calculated. This instrument is available, with all 31 items including the four dropped from analysis in this article, from the authors (see http://depts.washington.edu/~eolcare.)

Additional Questions. In addition to the QODD, respondents completed a number of additional questionnaires and questions. To assess symptoms of decedents prior to death, we modified the Memorial Symptom Assessment Scale[10] to be administered after death to a family member (this instrument has not been previously validated for use in this way). To assess place and preferences for death, symptom treatment, advance directives, patient preferences for end-of-life care, the quality of communication with the health care team, and satisfaction with care, we used individual items adapted from the SUPPORT questionnaires[4] and the Toolkit of Instruments to Measure the End Of Life (Toolkit).[11] In addition, we developed a series of questions about spiritual experiences that the decedent had prior to death (questions available on request) and two global rating questions about the quality of life during the patient's last seven days and the quality of the patient's moment of death. Demographic questions (e.g., age, sex, race/ethnicity, marital status, education level, household income) were also included.

Medical Record Review. Medical records were reviewed for 185 of the 205 (90%) decedents for whom a QODD questionnaire was completed. Trained chart abstracters conducted the medical record review using a form adapted from the Toolkit.[11] If decedents died in the hospital, inpatient hospice setting, or nursing home, the corresponding institutional medical record was reviewed. If decedents died outside one of these institutions, outpatient medical records were reviewed. The major purpose of the medical record review was to determine the circumstances of death and document the intensity of medical care provided to decedents.

Statistical Analyses

The measurement validity of the QODD was examined using MAP-R.[12] QODD item and total score characteristics were examined for percent missing, percent of scores at the top and bottom of the response scale (0 or 10 for items, 0 or 100 for the total score), means, standard deviations, and skew. For items, we expected missing responses and scores of 0 and 10 to be characteristic of less than 15% of the respondents. We expected the distributions to be approximately normal with skew < 3.0.[13] For analyses in this article, we focussed on the QODD total score. For the total QODD score, we expected less than 5% missing responses, no scores of "0" or "100", and a normal distribution with a skew < 2.0. We also examined the internal consistency of the QODD total score using Cronbach's alpha. We expected a value greater than 0.70, the standard used for defining an acceptably reliable instrument for group comparisons.[13]

For construct validity, we expected a higher QODD total score to be significantly and positively associated with: deaths at home, deaths that corresponded to previously discussed patient preferences, lower symptom scores, better symptom treatment, adherence to patient preferences for end-of-life care, better quality of communication with the health care team, better satisfaction with care, lower intensity of care, and more religious and spiritual experiences. With the exception of symptom scores and the global rating items that were measured continuously and analyzed with Pearson correlations, all other variables were assessed with t tests (dichotomous variables) or ANOVA (multi-category variables). Differences between groups identified with ANOVA analyses were explored with Scheffe's pairwise comparisons. For correlations, we expected significantly meaningful associations to have an $r \geq 0.40$. In order to limit the error rate due to multiple comparisons, we set the threshold for statistical significance at $P < 0.01$ and the threshold for a statistical trend at $P = 0.05–0.01$.

For all analyses, we used the decedent as the unit of analysis. Although physicians, nurses, and individual systems provided care for multiple decedents, we did not account for this clustering in our analyses of instrument performance. However, to assess the potential role of clustering of providers on the association between QODD total score and quality of care, we restricted each physician to 1 or 2 patients and repeated these analyses. There were no substantial differences in point estimates (although statistical significance was not always the same due to smaller sample sizes). Because there were no important changes, analyses presented are those with all subjects.

Results

Respondents vs. Non-Respondents

Table 1 shows the characteristics of the decedents for those 252 family members who consented to an in-person interview compared with the 683 decedents for whom no interview was conducted. Table 1 also shows the characteristics of non-respondents who refused participation ($n = 440$). These characteristics were determined from the death certificate and there

Table 1
Comparison of Respondents, Non-Respondents, and Refusals

	Respondents (*n*=252)	Non-Respondents (*n*=683)	P	Refusals (*n*=440)	P
Decedent Characteristics	Mean (sd)	Mean (sd)		Mean (sd)	
Age	71.98 (18.47)	70.91 (20.00)	0.459	72.79 (19.12)	0.587
	% (n)	% (n)		% (n)	
Gender: female	48.8 (123)	47.1 (322)	0.651	46.8 (206)	0.614
Cause of Death:			0.578		0.649
Heart Disease	28.6 (72)	24.7 (169)		24.3 (107)	
Malignant Neoplasms	26.6 (67)	24.0 (164)		24.3 (107)	
Cerebrovascular Diseases	7.5 (19)	7.9 (54)		9.3 (41)	
COPD	6.0 (15)	7.6 (52)		7.5 (33)	
Accidents and Adverse Effects	5.2 (13)	5.3 (36)		3.9 (17)	
Pneumonia and Influenza	2.8 (7)	3.8 (26)		4.5 (20)	
Diabetes Mellitus	0 (0)	1.2 (8)		1.4 (6)	
Suicide	1.2 (3)	3.2 (22)		2.0 (9)	
Nephritis, Nephrotic Syndrome, Nephrosis	1.6 (4)	1.8 (12)		1.8 (8)	
Chronic Liver Disease and Cirrhosis	1.2 (3)	1.2 (8)		.7 (3)	
Dementia	2.8 (7)	3.4 (23)		4.1 (18)	
Neurologic	2.8 (7)	2.5 (17)		2.3 (10)	
Other	10.7 (27)	8.6 (59)		9.5 (42)	
Cause Unknown	3.2 (8)	4.8 (33)		4.3 (19)	
Place of Death:			0.913		0.857
Hospital	33.3 (84)	30.7 (210)		31.8 (140)	
Hospice House	6.7 (17)	7.5 (51)		7.7 (34)	
Nursing Home	22.6 (57)	21.8 (149)		24.3 (107)	
ER	3.6 (9)	5.1 (35)		5.2 (23)	
Home	20.6 (52)	21.5 (147)		19.5 (86)	
Out of Hospital-sudden/traumatic	4.0 (10)	5.0 (34)		4.5 (20)	
Out of Hospital-sudden/non-traumatic	7.1 (18)	5.9 (40)		4.8 (21)	
Other	2.0 (5)	2.5 (17)		2.0 (9)	
Residence at Time of Death, %(*n*)			.334		.196
Home	67.5 (170)	71.0 (485)		69.3 (305)	
Nursing Home	24.2 (61)	23.0 (157)		25.9 (114)	
Senior Residence	5.2 (13)	4.5 (31)		3.6 (16)	
Other (assisted living, PCA home)	3.2 (8)	1.5 (10)		1.1 (5)	
Respondent Characteristics					
Sex					
female, % (*n*)	74.2 (187)	61.3 (417)	0.001	60.7 (267)	0.001
Respondent Relationship			0.001		0.001
Wife/Female Partner	23.8 (60)	24.3 (166)		24.8 (109)	
Husband/Male Partner	6.0 (15)	9.5 (65)		9.8 (43)	
Brother/Sister	4.0 (10)	5.9 (40)		5.7 (25)	
Daughter	33.3 (84)	21.1 (144)		22.3 (98)	
Son	13.9 (35)	17.9 (122)		19.5 (86)	
Father/Mother/Guardian	5.6 (14)	8.5 (58)		6.8 (30)	
Extended Family Member	6.3 (16)	3.8 (26)		3.6 (16)	
Friend	5.2 (13)	2.0 (14)		1.6 (7)	
Service Provider	1.2 (3)	1.3 (9)		1.1 (5)	
Unknown	.8 (2)	5.7 (39)		4.8 (21)	
Other Factors					
No funeral service	12.7 (32)	14.5 (99)	0.483	14.3 (63)	0.551
Number of days between death and interview, mean (SD)	708.1 (222.7)	679 (219)	0.075	652.6 (219.9)	0.002

were no significant differences in the decedents' age, sex, place of death, cause of death, or residence at the time of death. However, significantly more respondents than non-respondents and refusals were female, daughters, or friends. Refusals also had fewer days between the decedent's death and interview (653 days vs. 708 days) than respondents did.

Sample Characteristics

Table 2 shows the demographic characteristics for the 205 decedents and respondents for whom QODD interviews were completed. Decedents and respondents were primarily white with a wide range of education and income. A total of 81% of the QODD respondents (n = 166) completed questions about

Table 2

Demographics of the Decedents and Respondents for Whom a QODD Questionnaire Was Completed

	Decedents (*n*=205)	Respondents (*n*=205)
Age, Mean (SD)	74.89 (15.52)	56.5 (13.12)
Sex, % (*n*)		
Female	50.2 (103)	74.1 (152)
Race/Ethnicity		
White	95.1 (195)	96.6 (198)
Marital Status		
Married	38.5 (79)	54.1 (111)
Education		
< 8th grade	3.9 (8)	0 (0)
8–11th grade	26.8 (55)	5.9 (12)
12th grade	27.3 (56)	21.0 (43)
Some college	19.5 (40)	31.2 (64)
College	12.7 (26)	22.9 (47)
Post-college	6.3 (13)	19.0 (39)
Income		
<$15,000	44.9 (92)	19.0 (39)
$15,000–$30,000	23.9 (49)	25.9 (53)
>30,001	23.9 (49)	47.3 (97)
Respondent Relationship to Decedent		
Spouse		27.8 (57)
Adult child		51.7 (106)
Other family member		13.2 (27)
Other–friend, provider		7.3 (15)

their loved one's last seven days of life; 19% completed questions about their loved one's last 30 days.

Measurement Validity

QODD Item Characteristics. Missing responses on QODD items, including both "don't know" and "not applicable" answers, ranged from 1% for the item "having enough energy" to 23% for "having means to end one's life". Six items had missing responses for more than 15% of the respondents: being at peace with dying (17%), spending time with children (17%), finding meaning and purpose in life (18%), state of consciousness at end of life (20%), having a religious or spiritual ceremony (21%), and having means to end one's life (23%). The percent of respondents scoring 10 (almost perfect experience) ranged from 2% for having enough energy to 50% for being hugged and touched. All except 6 of the 27 items had more than 15% of respondents scoring at the item's ceiling. The percent of respondents scoring 0 (terrible experience) ranged from 1.5% for being hugged and touched, having a visit from religious or spiritual leader, and having a religious ceremony before death to 30.7% for having enough energy. Five items had more than 15% of respondents scoring a 0: having control (15.1%), feeding oneself (17.1%), breathing comfortably (18.0%), having control of bowel and bladder (23.4%), and having enough energy (30.7%). Mean scores for items ranged from 2.71 for having enough energy to 8.80 for being hugged and touched. None of the distributions were skewed at >3.00.

QODD Total Score Characteristics. The QODD total score ranged from 26.00 to 99.62. No deaths were scored at either 0 or 100. Only 6 decedents (3%) were scored at or above a score of 95. The QODD distribution was approximately normal, with minimum skew (−0.37), a mean of 67.36, and a standard deviation of 15.06 (Figure 1). The Cronbach's alpha for the QODD total score was 0.89.

Construct Validity

Decedent and Respondent Characteristics. As shown in Table 3, there were no significant differences in the QODD total score by decedent or respondent demographics including sex, education level, marital status, or household income. The QODD score did not vary by race/ethnicity, but the vast majority of decedents and respondents were white. QODD total scores also did

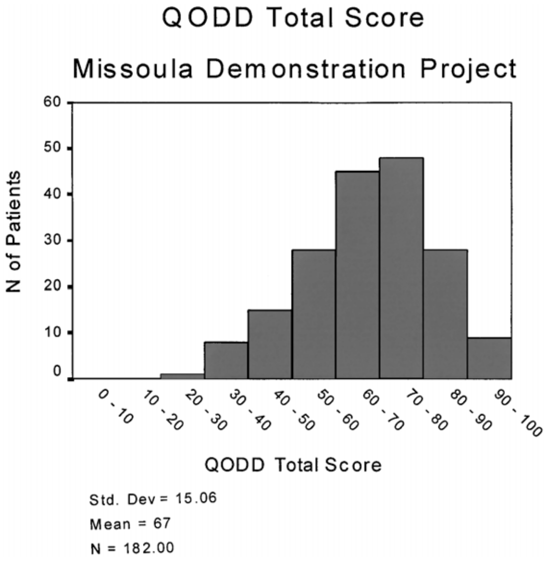

Fig. 1. QODD total score. Missoula demonstration project.

Table 3

The QODD Total Score by Decedent and Respondent Characteristics, Place, and Preferences for Death

	n	MEAN	SD	ANOVA/*t*-Test
Decedent Characteristics				
Age				0.116
18–64	43	64.43	17.80	
65–74	23	63.15	15.85	
75–84	59	70.32	13.65	
85+	57	68.21	13.41	
Sex				0.208
Male	89	68.80	14.40	
Female	93	65.98	15.62	
Race				0.971
White	173	67.50	14.99	
Non-white	8	67.30	12.36	
Education				0.447
<8th grade	7	63.52	19.50	
8–11th grade	49	69.56	13.88	
12th grade	49	68.32	14.19	
Some college	38	65.86	15.48	
College	25	64.41	15.73	
Post-college	9	74.09	17.95	
Marital status				0.125
Not married	109	65.81	15.71	
Married	72	69.30	13.54	
Income				0.152
<$15,000	80	64.99	14.06	
$15,001–$30,000	47	70.36	15.61	
>$30,001	44	66.42	16.22	
Place, Preferences for Death				
Place of death = home				0.006
No	136	65.57	14.79	
Yes	46	72.65	14.76	
Dying in desired place				0.013
No	53	64.99	15.85	
Yes	59	72.06	13.64	
Respondent Characteristics				
Age				0.047
<40	15	58.55	14.75	
40–50	44	62.27	14.09	
50–65	73	68.86	15.83	
65+	50	69.67	14.02	
Sex				0.750
Male	46	66.75	14.75	
Female	136	67.57	15.21	
Race				0.270
White	175	67.73	14.91	
Non-white	6	60.85	17.42	
Education				0.986
<8th grade	0	66.28	13.11	
8–11th grade	12	66.96	13.96	
12th grade	41	68.33	16.95	
Some college	57	67.08	15.12	
College	38	66.93	14.29	
Post-college	34	67.36	15.06	
Marital status				0.974
Not married	83	67.16	14.77	
Married	98	67.23	15.16	
Income				0.316
<$15,000	35	63.57	15.59	
$15,001–$30,000	49	68.56	14.94	
>$30,001	85	67.20	15.03	
Length of relationship with decedent				0.398
<10 years	6	60.01	9.93	
11–20 years	10	70.44	14.28	
21–40 years	38	64.62	16.73	
41–60 years	84	68.96	14.32	
60+ years	25	67.28	15.58	

Table 4
QODD Total Score Construct Validation

	n	MEAN	SD	ANOVA/*t*-Test
Symptom Experience and Treatment				
During the last month, did you feel the doctor could have done more to help control x’s symptom?				0.007
No	153	68.51	14.47	
Yes	24	59.50	17.75	
During the last month, did you feel the nurse could have done more to help control x’s symptom?				0.042
No	155	68.52	15.06	
Yes	18	60.93	13.28	
During the last month, did x have to wait too long to be treated for his/her symptom?				0.006
No	139	69.24	14.55	
Yes	32	61.29	15.08	
Advance Directives and Preferences for End-of-Life Care				
Did x have a signed Living Will?				0.103
No	47	64.21	16.82	
Yes	132	68.40	14.44	
Did x have a signed Durable Power of Attorney for Healthcare?				0.675
No	44	66.73	16.51	
Yes	130	67.84	14.64	
Before x died, did you ever discuss issues of death and dying with him/her?				0.009
No	46	62.42	15.53	
Yes	135	69.12	14.60	
How much were x’s preferences for medical care followed during the last seven days/last month of his/her life?				0.001
0 (none), 1, 2	9	59.39	12.66	
3 (some), 4	27	51.66	13.48	
5 (good deal)	43	71.87	12.29	
6 (very great deal)	82	71.58	13.14	
Communication with the Health Care Team, Satisfaction with Care				
How much did the health care team involve you in making decisions about treatment for x ?				0.075
0 (none), 1,2	38	63.41	15.14	
3, 4	29	65.33	14.29	
5, 6 (a very great deal)	109	69.35	14.73	
How well did the health care team listen to you?				0.001
0 (worst possible way)–4	19	61.88	13.40	
5, 6, 7	27	60.88	13.11	
8, 9	59	65.88	15.17	
10 (best possible way)	68	72.28	14.19	
How well did the health care team explain x’s condition to you?				0.002
0 (worst possible way)–4	20	60.21	14.20	
5, 6, 7	18	61.15	14.52	
8, 9	53	65.98	15.11	
10 (best possible way)	82	71.29	13.61	
Did a member of the health care team talk to you about what would happen during x ’s final hour of life?				0.244
No	99	66.01	15.56	
Yes	77	68.71	14.82	
Was there a doctor who you feel was primarily responsible for x’s care?				0.029
No	15	59.57	16.53	
Yes	166	68.28	14.55	
Was there a member of the health care team who made sure that x got the best care he/she could get?				0.021
No	17	59.98	13.34	
Yes	153	68.69	14.78	
If a problem developed at night or on the weekend, was there a member of the health care team who was available and who was familiar with x ?				0.001
No	19	55.6	14.83	
Yes	150	68.68	14.46	

not vary significantly by decedents' age, but scores from respondents aged forty or younger were lower than scores from respondents aged 65 or greater; this difference did not achieve statistical significance, but reached our a priori threshold for a statistical trend ($P = 0.047$). There were no significant differences on the QODD total score by length of time the respondent had known the decedent. There was also no significant correlation between the QODD score and the number of days between the death and the after-death interview ($r = -0.10$; $P = 0.17$). There were, however, differences by location of death. Decedents who died at home had a significantly higher QODD score than those dying in other settings ($P = 0.006$). Decedents who died in the setting where the respondent told us they had wanted to die also had higher QODD scores that approached our definition of statistical significance ($P = 0.013$).

Symptom Experience and Treatment. Using an adaptation of the Memorial Symptom Assessment Scale (MSAS), we found a significant correlation between the MSAS and the QODD score, such that higher total symptom burden was correlated with lower QODD scores ($r = -0.52$; $P = 0.001$). Similarly, there were significant correlations between the QODD score and the MSAS psychological sub-score ($r = -0.47$; $P = 0.001$) and the MSAS physical subscore ($r = -0.42$; $P = 0.001$). These correlations remained statistically significant with little change in magnitude when the symptom-related items of the QODD (items 1, 4–6) are omitted from the total score (e.g., total MSAS $r = -0.47$; $P = 0.001$; psychologic subscale $r = -0.46$, $P = 0.001$; physical MSAS $r = -0.39$, $P = 0.001$.) We asked respondents a series of questions about the treatment of symptoms. Table 4 shows the association between the QODD score and responses to these questions. There were significant differences on the QODD total score for some symptom treatment questions. If the respondents reported that physicians could have done more to help control symptoms or that the decedents waited too long for pain medication, the QODD scores were significantly worse ($P < 0.01$). There was a trend toward an association between reports that a nurse could have done more to help control symptoms and a worse QODD score, but this association did not achieve statistical significance ($P = 0.042$).

Advance Directives and Preferences for End-of-Life Care. The QODD score was not significantly associated with the presence of a living will or a durable power of attorney for healthcare (Table 4). However, respondents who reported that the decedent had discussed their preferences for end-of-life care with a loved one or reported that the decedent's preferences for care were followed most of the time scored significantly higher on the QODD ($P < 0.01$).

Communication with the Health Care Team and Satisfaction with Care. There were several items assessing communication with the health care team and satisfaction with care (Table 4). Among the items assessing communication, the QODD score was higher for respondents reporting that the health care team listened ($P = 0.001$) and the health care team did a good job explaining the decedent's condition ($P = 0.002$). These associations did not change if the item concerning discussing end-of-life wishes with your doctor (item 13) was deleted from the QODD (data not shown). Conversations between the respondent and a member of the health care team about what would happen in the decedent's final hours were not associated with higher QODD scores. Some items assessing satisfaction with care were associated with higher QODD scores (having a familiar team member available at night and weekends; $P < 0.001$) while other satisfaction with care items showed a trend toward statistical significance (a member of the health care ensured patients got the best care possible, $P = 0.02$; a single physician primarily was responsible for care, $P = 0.03$).

Intensity of Care. Neither the use of intensive care nor mechanical ventilation during the last month of the decedent's life was significantly associated with the QODD score. Further, while increasing numbers of invasive treatments (including mechanical ventilation, hemodialysis, right heart catheterization) were associated with lower QODD scores (68.2 for none; 66.8 for one, 60.8 for two or more), this association approached, but did not achieve, our threshold for statistical significance ($P = 0.063$).

Table 5
The QODD Total Score By Patients' Spiritual and Religious Experiences

	n	MEAN	SD	ANOVA/*t*-Test
Did x identify him/herself with an organized religion or have a spiritual orientation?				0.222
No	37	64.6	15.29	
Yes	145	68.07	14.97	
Did someone on the health care team talk with x about his/her spiritual or religious concerns				0.332
No	103	66.46	15.15	
Yes	55	68.94	15.44	
Did any of the following experiences/practices give x comfort over the last months of his/her life?				
Opportunity to fulfill one last dream?				0.001
No	125	64.8	14.98	
Yes	54	73.77	13.4	
Reading/being read to from a spiritual book?				0.047
No	106	65.49	15.03	
Yes	76	69.98	14.81	
Opportunity to make amends before dying?				0.731
No	118	66.86	15.29	
Yes	61	67.68	14.79	
Opportunity to talk with spiritual leader, counselor from spiritual community?				0.019
No	93	64.99	15.21	
Yes	88	70.18	14.3	
Support of friends from x 's spiritual group?				0.048
No	92	65.17	15.21	
Yes	89	69.61	14.74	
Going to a church or place of worship				0.022
No	131	65.77	14.58	
Yes	51	71.46	15.64	
Having a chance to ask questions about beliefs, faith, life after death, survival of the spirit?				
No	108	66.1	15.54	
Yes	73	69.04	14.26	
Final rites of x 's faith community?				0.278
No	121	66.54	15.39	
Yes	59	69.14	14.39	
Praying together as a family or community?				0.006
No	108	64.82	14.73	
Yes	74	71.07	14.86	
Receiving assurances from family that final wishes would be followed?				0.905
No	30	67.19	16.61	
Yes	150	67.55	14.74	

Spiritual and Religious Experiences. As shown in Table 5, two spiritual and religious experiences were associated with higher QODD scores (fulfilling one last dream and praying together as a family or community; $P < 0.01$). Being read to from a spiritual book, talking with a spiritual leader or counselor, having the support of friends from a spiritual group, and going to a church or place of worship were associated with higher QODD scores to a degree that approached statistical significance ($P = 0.05$–0.01). Religious or spiritual experiences that were not associated with higher QODD scores included identifying with an organized religion or having a spiritual orientation, talking with the health care team about religious or spiritual concerns, making amends before dying, having a chance to talk about beliefs, and participating in final rites of a faith community.

QODD Total Score Compared to Global Ratings. After completing the QODD, respondents were asked two global rating questions. First, they were asked, "How would you rate the quality of (*patient name*)'s life during the last seven days of his/her life?" The scale rating was from 0 (terrible) to 10 (almost perfect). This single item was significantly correlated with the QODD total score ($r = 0.55$; $P < 0.001$). Next, respondents were asked, "How would you rate the quality of (*patient name*)'s moment of death?" on the same scale. This single item was also significantly correlated with the QODD total score ($r = 0.51$; $P < 0.001$). Using linear regression with the QODD total score as the outcome variable, these two global rating questions explained 38% of the variance in the QODD total score ($r = 0.63$; $P < 0.001$).

Discussion

The current study demonstrates preliminary support for the cross-sectional and construct validity of the Quality of Dying and Death instrument. The findings show that the QODD total score has favorable measurement properties, with a normal distribution, no significant floor or ceiling effects, and excellent internal consistency reliability. The QODD total score was significantly associated in the hypothesized directions with constructs related to the quality of dying and death. Death at home, less symptom burden, better symptom treatment, better communication, and higher satisfaction with care were all associated with higher QODD scores. These data suggest that this qualitatively and empirically derived questionnaire[6] may be a useful tool for evaluating and modifying end-of-life experiences.

A number of the findings from this study provide direction for clinical care. First, we have shown that clinician–patient and clinician–family communication about end-of-life care are associated with a better rating of the dying experience by family members. There has been considerable research on the occurrence of communication between physicians and patients[4,14] and some research examining the quality of this communication.[15–17] Our findings represent the first empiric demonstration that this communication is associated with a better quality dying experience. Furthermore, the components of communication that were associated with the QODD score may provide useful insights for clinicians. How well the health care team listens to the family was strongly associated with QODD score. Tulsky and colleagues have shown that when physicians are talking with patients about advance directives and Do Not Resuscitate orders, they spend almost 75% of the time talking and only 25% of the time listening.[16,17] Our findings suggest listening is an important area to improve quality of care. Another important feature of communication was explaining the patient's condition. Education of the patient and family in language they can understand and in terms that are meaningful in their lives is another important aspect of communication about end-of-life care.[18]

A second finding important for clinicians and health care organizations is the association between accessibility of the providers and the quality of the dying experience. Having someone available at night or weekends familiar with the patient was significantly associated with a better QODD score. In addition, two aspects of care trended toward a significant association with higher quality dying: having a physician primarily responsible for the patient's care and having a member of the health care team who made sure that the patient got the best care possible.

A final aspect of care that may be important for clinicians and health care organizations was the association between spiritual and religious experiences and the quality of the dying experience. While the health care organization may not be able to provide these experiences for all patients, these findings do suggest that if health care organizations support access to these services or at least do not create barriers to these services, such access may improve the quality of the dying experience for some patients.[19]

An additional finding of interest is the lack of association between the intensity of care received during the last month of life and scores on the QODD. Although there was a trend toward more invasive treatments being associated with poorer quality of dying and death, this trend did not meet our threshold for statistical significance. There is growing interest in examining and improving end-of-life care in the intensive care unit.[20] Our findings suggest that spending time in the ICU in the last month of life was not strongly associated with the quality of dying and may be an acceptable or even "good" quality of the dying experience for some patients. Further research is needed to explore the association between the intensity of care and the quality of the dying experience and the influence of treatment preferences on this association.

In addition to the QODD questions, we asked respondents two global questions rating the quality of life in the last seven days and the quality of the moment of death. These global rating questions were significantly associated with the QODD total score; both questions combined explain 38% of the variance in the QODD total score. Future research is necessary to determine whether, in some settings where resources for instrument administration and scoring are limited, these global rating questions might suffice to assess important variation in the quality of the dying experience.[21] Global rating questions might be particularly useful in quality improvement settings where administering and scoring a multi-item instrument may be prohibitive.

It is important to differentiate the concepts of quality of life at the end of life, quality of end-of-life care, and the quality of dying and death.[22] Considerable attention has been paid to quality of life measurement at the end of life.[22–29] Similarly, researchers have investigated the quality of medical care at the end of life[30] and there is a strong interest in developing and using measures of the quality of care at the end of life.[11,31] If we are to identify interventions and quality improvement efforts that improve the dying experience, we must have reliable, valid, and responsive measures of the quality of the dying experience. We have provided information suggesting that the QODD may be able to serve this role and that further studies are warranted to investigate its usefulness in this role.

Although the QODD has performed well in this study as a measure of the quality of the dying experience, there are a number of important methodologic challenges that need consideration and evaluation. Because it is not possible to assess the patient's experiences of the dying process after death, we have chosen to assess the experience from the memory of family members. However, family members have their own burdens and stressors as a loved one is dying[32,33] and their assessments may be shaped by their own experiences or grief or other complicating factors, such as guilt.[9,34] Furthermore, different family members may have very different perspectives on the patient's experience and the assessment of the quality of death could be affected by the time from death to the assessment.[9] Although we found no systematic differences in QODD scores across respondent characteristics, such as relationship with the deceased or time from death to assessment, this finding does not rule out important biases by family respondents or time to interview. Health care providers may be another source of information, but may spend only limited time with patients during the dying process and may have their own biases. Future research is needed to examine agreement across raters, the meaning of disagreements that will exist, methods of identifying the "most accurate" rater, and the most appropriate timing after death for administration of the QODD.[9]

Because we cannot capture the patient's views after death, perhaps we should examine their views and preferences prior to death. Quality of death was defined by the Institute of Medicine as a death that is "free from avoidable distress and suffering for patients and their families, in accord with the patients' and families' wishes, and reasonably consistent with clinical, cultural, and ethical standards".[1] The Institute of Medicine's definition of quality of dying and death and our operational definition[6] both incorporate patient preferences. Further research is needed to determine whether measurement of patients' preference about the dying experience should be used to modify the assessment of the quality of the dying experience provided by family members after death.

In addition to these methodologic challenges of measuring the quality of dying, our study has a number of specific limitations. We identified all deaths in Missoula County in 1996 and 1997, providing us with a population-based sample, but had a response rate of 27% of those deaths and 36% of those potential respondents that we could contact. Although the demographics and cause of death of decedents were very similar for respondents and nonrespondents, there may still be important differences between the two groups. These differences would not affect the internal validity of this study for our sample, but they could affect the generalizability to other populations. Furthermore, Missoula County differs from many other areas in terms of racial and ethnic mix, religion, and other demographic characteristics that may limit the generalizability of this study. Further research is needed with larger sample sizes to assess whether this instrument would perform better if divided into subscales. Finally, this validation of the QODD depends in large part on the reports of the same respondent who completed the QODD. Some of the correlation may exist because an individual respondent may be predisposed to answer all questions in a relatively positive or negative way. We attempted to counter this limitation by comparing the QODD score to specific reports, such as whether a healthcare provider familiar with the patient was available for evening or weekend calls, and to medical record-based information such as the location of death, that should be less affected by this limitation. In addition, correlation between the QODD and some constructs, such as symptom burden, may be increased because related concepts, symptoms during the dying experience, are in the QODD. However, when omitting items concerning symptoms, the correlation with symptom burden is unchanged. Similarly, omitting the QODD item concerning communication with the healthcare team did not alter the association with communication.

We have presented data suggesting that the QODD provides a valid assessment of the quality of the dying experience and warrants further investigation as an outcome measure to identify excellent quality end-of-life care, test interventions to improve the quality of care, and assess quality improvement projects. Furthermore, our data provide support for improving pain and symptom management, and improving communication between patients, families, and the health care team as a basis for improving the dying experience. Our data also provide impetus for health care organizations to structure end-of-life care to insure accessibility to an individual who is familiar with the patient, available during weekends and evenings, and able to ensure that patients and families receive the best care possible. These data also imply the importance of insuring continuity of physician care through the end of life. Finally, these data suggest that facilitation of religious and spiritual experiences desired by patients and families may also improve the dying experience. The development, refinement, and promulgation of tools to measure the quality of the dying experience will facilitate improving the quality of care at the end of life.

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References

1. Field MJ, Cassel CK. Approaching death: improving care at the end of life. Institute of Medicine Report. Washington, DC: National Academy Press, 1997.

2. Schneiderman LJ, Kronick R, Kaplan RM, et al. Effects of offering advance directives on medical treatments and costs. Ann Intern Med 1992;117: 599–606.

3. Danis M, Southerland LI, Garrett JM, et al. A prospective study of advance directives for life-sustaining care. N Engl J Med 1991;324:882–888.

4. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). JAMA 1996;274:1591–1598.

5. Lo B. Improving care near the end of life: why is it so hard? JAMA 1995;274:1634–1636.

6. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. J Pain Symptom Manage 2001;22:717–726.

7. Layde PM, Broste SK, Desbiens N, et al. Generalizability of clinical studies conducted at tertiary care medical centers: a population-based analysis. J Clin Epidemiol 1996;49:835–841.

8. Hanson LC, Earp JA, Garrett J, et al. Community physicians who provide terminal care. Arch Intern Med 1999;159:1133–1138.

9. Fowler JF, Coppola KM, Teno JM. Methodological challenges for measuring quality of care at the end of life. J Pain Symptom Manage 1999;17:114–119.

10. Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. Eur J Cancer 1994;30A:1326–1336.

11. Teno JM, Byock IR, Field MJ. Research agenda for developing measures to examine quality of life of patients diagnosed with life-limiting illness. J Pain Symptom Manage 1999;17:75–82.

12. Ware JE, Harris WJ, Gandek B, et al. MAP-R for Windows: multitrait/multiitem analysis program—revised user's guide. Boston: Health Assessment Lab, 1997.

13. Stewart AL, Ware JE. Measuring functioning and well being: the medical outcomes study approach. Durham, NC: Duke University Press, 1992:449.

14. Hofmann JC, Wenger NS, Davis RB, et al. Patients' preferences for communication with physicians about end-of-life decisions. Ann Intern Med 1997;127:1–12.

15. Curtis JR, Patrick DL, Caldwell E, Greenlee H, Collier AC. The quality of patient-clinician communication about end-of-life care: a study of patients with AIDS and their primary care clinicians. AIDS 1999;13:1123–1131.

16. Tulsky JA, Fischer GS, Rose MR, Arnold RM.

Opening the black box: how do physicians communicate about advance directives? Ann Intern Med 1998;129:441–449.

17. Tulsky JA, Chesney MA, Lo B. See one, do one, teach one? House staff experience discussing do-not-resuscitate orders. Arch Intern Med 1996;156: 1285–1289.

18. Curtis JR, Wenrich MD, Carline JD, et alG. Understanding physicians' skills at providing end-of-life care: perspectives of patients, families, and health care workers. J General Intern Med 2001;16:41–49.

19. Steinhauser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. Ann Intern Med 2000;132: 825–832.

20. Curtis JR, Rubenfeld GD. Managing death in the ICU: the transition from cure to comfort. New York: Oxford University Press, 2001.

21. Donnelly S, Walsh D. Quality of life assessment in advanced cancer. Palliat Med 1996;10:275–283.

22. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. J Pain Symptom Manage 1999;17:93–108.

23. Byock IR, Merriman MP. Measuring quality of life for patients with terminal illness: the Missoula-VITAS quality of life index. Palliat Med 1998;12: 231–244.

24. Cohen SR, Mount BM, Strobel MG, Bui F. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. Palliat Med 1995;9:207–219.

25. Cohen SR, Mount BM, Bruera E, et al. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. Palliat Med 1997;11:3–20.

26. Morris JN, Suissa S, Sherwood S, et al. Last days: a study of the quality of life of terminally ill cancer patients. J Chron Dis 1986;39:47–62.

27. Ventafridda V, De Conno F, Ripamonti C, et al. Quality of life assessment during a palliative care programme. Ann Oncol 1990;1:415–420.

28. Wallston KA, Burger C, Smith RA, Baugher RJ. Comparing the quality of death for hospice and non-hospice cancer patients. Medial Care 1988;26: 177–182.

29. Greer DS, Mor V, Morris JN, et al. An alterhative in terminal care: results of the National Hospice Study. J Chron Dis 1986;39:9–26.

30. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspective. JAMA 1999;281:163–168.

31. Lynn J. Measuring quality of care at the end of life: a statement of principles. J Am Geriatr Soc 1997;45:526–527.

32. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. Ann Intern Med 2000;132:451–459.

33. Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. JAMA 1994; 272:1839–1844.

34. Hinton J. How reliable are relatives' retrospective reports of terminal illness? Patients' and relatives' accounts compared. Soc Sci Med 1996;43:1229–1236.

Appendix:

Items for Measuring the Quality of Dying and Death (QODD)

Each item was asked with the following leader: "How would you rate this aspect of (*patient's name*) dying experience?" The response scale was from 0 to 10 where 0 was a "terrible experience" and 10 an "almost perfect experience".

1. Having pain under control.
2. Having control of event.
3. Being able to feed oneself.
4. Having control of bladder, bowels.
5. Being able to breathe comfortably.
6. Having energy to do things one wants to do.
7. Spend time with your children as much as you want. (*or I have no children*)
8. Spend time with your friends and other family as much as you want.
9. Spend time alone.
10. Be touched and hugged by loved ones.
11. Say goodbye to your loved ones.
12. Have the means to end your life if you need to.
13. Discuss your wishes for end-of-life care with your doctor and others.
14. Feel at peace with dying.
15. Avoid worry about strain on your loved ones.
16. Be unafraid of dying.
17. Find meaning and purpose in your life.
18. Die with dignity and respect.
19. Laugh and smile.
20. Avoid being on dialysis or mechanical ventilation.
21. Location of death (home, hospice, hospital).
22. Die with/without loved ones present.
23. State at moment of death (awake, asleep).
24. Have a visit from a religious or spiritual advisor.
25. Have a spiritual service or ceremony.
26. Have health care costs provided.
27. Have funeral arrangements in order.
28. Spend time with spouse, partner. (*or I have no spouse, partner*)
29. Spend time with pets. (*or I have no pets*)
30. Clear up bad feelings. (*or there were no bad feelings to clear up*)
31. Attend important events. (*or there were no important events to attend*)