

## Original Article

# Dying in the Hospital: What Happens and What Matters, According to Bereaved Relatives

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## Abstract

**Context.** Most deaths in Western countries occur in hospital, but little is known about factors determining the quality of dying (QOD).

**Objectives.** The aim was to assess the QOD in hospital as experienced by relatives and identify factors related to QOD.

**Methods.** A cross-sectional study on 18 wards of a university hospital in The Netherlands was conducted, including relatives of patients who died after an admission of more than six hours, from June 2009 to March 2011. Relatives' perceptions of QOD and quality of care and the relation between dimensions of QOD and overall QOD scores were assessed.

**Results.** Two hundred forty-nine relatives participated (51%) and rated overall QOD at 6.3 (SD 2.7; range 0–10). According to relatives, patients suffered from 7.0 (SD 5.8) of 22 symptoms and were at peace with imminent death in 37%. Patients had been aware of imminent death in 26%, and relatives were aware in 49%. Furthermore, 39% of patients and 50% of relatives had said good-bye, and 77% of patients died in the presence of a relative. Symptom alleviation was sufficient in 53%, and in 75%, sufficient efforts had been made to relieve symptoms. Characteristics of QOD and quality of care could be summarized in nine domains, explaining 34% of the variation of QOD scores. Medical, personalized, and supportive care were most strongly related to QOD.

**Conclusion.** Relatives rated QOD as sufficient. A majority of patients and relatives were not sufficiently prepared for imminent death, and relatives experienced many problems. QOD appears to be a multidimensional construct, strongly affected by medical care and staff attentiveness. *J Pain Symptom Manage* 2015;49:203–213. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

Hospitals, palliative care, quality of dying, relatives, terminal care

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## Introduction

In most Western countries, more than 50% of deaths occur in hospital.<sup>1,2</sup> Some studies have reported on the satisfaction of health care professionals and relatives with end-of-life (EOL) care in the hospital;<sup>3,4</sup> others have found deficiencies and unmet needs of patients and relatives.<sup>5–14</sup> These deficiencies often relate to a lack of awareness that a patient is imminently dying, insufficient alleviation of symptoms,

inadequate communication, and the use of invasive procedures shortly before death.<sup>5–14</sup>

Research on the quality of dying (QOD) in hospitals involves conceptual, methodological, and ethical difficulties.<sup>15–22</sup> As a result, studies strongly differ in their conceptualization of QOD (e.g., with respect to the constituent factors and the time frame), research methodology (e.g., epidemiologic surveys, in-depth interviews), the populations studied (e.g., cancer patients, the elderly, intensive care patients), and

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Accepted for publication: June 26, 2014.

sources of information (e.g., patients, medical records, relatives, health care professionals).

QOD has been found to be a multidimensional construct, including physical, psychological, social, and spiritual experiences; life closure; death preparation and circumstances of death; and characteristics of health care at the EOL.<sup>21</sup> Another study showed that health care structures and processes can influence QOD experiences, in addition to patient-related factors.<sup>23</sup> Still, little is known about patients' and relatives' experiences at the very EOL in hospital and factors explaining these experiences.<sup>21</sup>

We aimed to contribute to better understanding of the experiences of patients and relatives in the last days of life and to identify factors that are related to the overall QOD.<sup>21</sup> We explored what, according to relatives, happens when patients die in hospital, and what matters, by assessing experiences and identifying factors that are related to the experience of either a good or a poor QOD.

## Methods

### Design

We performed a retrospective cross-sectional questionnaire study among relatives of patients who died in hospital. This study was part of a larger study to explore and understand palliative and terminal care in the hospital (PalTeC-H), which also involved physicians and nurses. More detailed information on the rationale and the study protocol has been published elsewhere.<sup>24</sup>

### Study Population and Data Collection

Erasmus MC, University Medical Center Rotterdam, is a 1300-bed general university hospital in The Netherlands. All adult patients who died between June 2009 and March 2011 on one of 18 wards in this hospital after an admission of at least six hours were eligible for the study. Because in The Netherlands most in-hospital deaths occur on regular wards in which processes of care strongly differ from those in intensive care units, the latter were not included in this study. For each eligible patient, one relative was asked to participate by filling out a written questionnaire. After a patient's death, a ward nurse informed relatives of this study; they could then provide the nurse with an address for sending written information and the questionnaire. In the absence of an address, an invitation was sent to the last address of the patient. Ten to 13 weeks after the patient died, the primary investigator (F. E. W.) invited a relative to complete a questionnaire. In case of no response after four weeks, one reminder was sent. Participants also could ask the investigator to complete the

questionnaire in an interview, for example, in cases of illiteracy or visual impairment.

### Ethical Considerations

Approval for this study was given by the Medical Ethical Research Committee of the Erasmus MC. According to Dutch legislation, written informed consent was not required because data were gathered after patients' deaths and the study involves minimal risk to the participants. In case of emotional distress as a result of completion of the questionnaire, participants were given the opportunity to call or meet the nurse investigator.

### Assessment

Patient characteristics, such as date of birth, gender, diagnosis, and the duration and ward of the patient's final admission, were derived from the medical file. An extensive questionnaire was developed by an expert group because available instruments did not meet our goals.<sup>25,26</sup> Our questionnaire included items on multiple dimensions of QOD, including physical, psychological, social, and existential experiences; life closure and death preparation; circumstances of death; and nature of health care.<sup>21</sup> We added specific items on relatives' satisfaction with EOL care.<sup>23,27</sup> We included relevant items of the Views Of Informal Carers Evaluation of Services questionnaire, the Leiden Detachment Scale, and the Quality of Dying and Death (QODD) questionnaire.<sup>27-29</sup> Preliminary versions of the questionnaire were critically reviewed by a representative of the hospital patient council, tested for relevance and face validity among persons who had recently lost a relative, and piloted in the 1st 30 cases. The final version of the questionnaire comprised 93 items, including one item on 14 physical symptoms (i.e., pain, dyspnea, coughing, death rattle, difficulty sleeping, fatigue, dry mouth, lack of appetite, nausea, swallowing problems, constipation, decreased consciousness, confusion, and agitation) and eight psychological symptoms (i.e., anxiety, loneliness, dependency, tenseness, worrying, sadness, feelings of powerlessness, depressed mood).

We used various scales, mostly gradually ascending, to allow for nuance, for example, a four-point scale (none/mild/moderate/severe) to assess the intensity of physical and psychological symptoms and three-point scales (yes, more or less, no) for most other items, which almost all concerned the last 24 hours of life. Overall QOD was assessed on a 0–10 numerical rating scale, asking "How would you evaluate the quality of dying of your relative?" with 0 being very poor and 10 almost perfect. Items evaluating care were explicitly referred to as hospital EOL care.

Table 1  
 Characteristics of Deceased Patients and Their Relatives

Characteristic	Total ( <i>n</i> = 249), <i>n</i> <sup>a</sup>	%	Median/Min–Max
<b>Patients</b>			
Age, yrs, mean (SD)	68.6 (13.9)		70/26–95
Gender			
Male	142	57	
<i>Marital status</i>			
Married/living with a partner	146	59	
Widowed/divorced/living alone/other	102	41	
Children			
One or more children <19 yrs	21	8	
Only children ≥19 yrs	173	70	
No	50	20	
Education			
Low (ISCED level 1–2)	78	31	
Intermediate (ISCED 3–4)	90	36	
High (ISCED 5–6)	48	19	
Other/unknown	33	13	
Religious			
Yes	115	48	
Diagnosis <sup>b</sup>			
Cancer	123	49	
Noncancer	126	51	
Duration of severe illness			
≤6 Months	101	41	
>6 Months	144	58	
Wards			
Nonsurgical wards	191	77	
Surgical wards	58	23	
Relatives involved in informal care, last 24 hours			
0 Relative	9	4	
1 Relative	39	16	
2 Relatives	85	34	
3 Relatives	78	31	
>3 Relatives	38	15	
Duration of last admission, mean (SD)	15.0 (21.3)		8/0–146
<b>Relatives</b>			
Age, yrs, mean (SD)	55.6 (12.9)		55/20–89
Gender			
Female	159	64	
Relation			
Partner/spouse	105	42	
Child (in-law)	93	37	
Other	51	21	

ISCED = International Standard Classification of Education. Variables related to QOD score in the univariate analysis are given in italics.

<sup>a</sup>*n* may not add up to the total because of missing values.

<sup>b</sup>Derived from patient records.

### Statistical Analysis

All three- and four-point variables were recoded into dichotomous variables: yes vs. more or less/no and none/mild vs. moderate/severe, to summarize the findings. The association between QOD scores and characteristics of care was analyzed in a six-step procedure: 1) linear regression analyses to test the relation of variables to the overall QOD score, while controlling for case characteristics; 2) selection of variables that were statistically significantly related to the QOD score with a *P*-value <0.10; 3) principal component analyses of selected variables to identify domains of the factors related to the QOD; 4) multiple imputation of missing values: we followed the formal adjustments of “multiple imputation, then deletion”<sup>30</sup> and set the number of replications at 22, being the highest percentage of missing values; seventeen cases (3%) were deleted

afterward because of a missing score on the outcome variable; 5) multivariate regression analysis to analyze the association between domains and QOD scores; and 6) multivariate regression analysis combining all domains, by forced entry of pooled parameters of each domain. Analyses were performed using SPSS 20 (SPSS/IBM, Chicago, IL).

### Results

During the study period, 524 cases were eligible for inclusion. Of these 524 cases, relatives of 32 patients (6%) could not be traced; in two cases, health care staff had objections to asking the relative to participate. Two hundred forty-nine relatives responded (response rate 51%). One participant requested a face-to-face interview to complete the questionnaire. The mean time

from the patient's death until completion of the questionnaire was 15.5 weeks (SD 3.4; range 10–31 weeks). No differences between responders and nonresponders were found for patients' gender, age, duration of last admission, and ward of last admission. Fifty nine of the 241 nonparticipating relatives reported having objections against participation in this study ( $n = 30$ ), having emotional problems ( $n = 19$ ), or having other reasons for not responding ( $n = 10$ ).

### Characteristics of Patients and Relatives

Mean age of the patients was 69 years (SD 14), and most patients were men (57%; Table 1). Fifty-nine percent had lived in partnership until the last admission, and 78% had children. Of all the patients, 48% were religious, of whom the large majority were Christian. Half of the patients were diagnosed with cancer. According to the relatives, 59% of the patients had been severely ill for more than six months, whereas 15% had been severely ill for less than one month. Most patients died on a nonsurgical ward (77%); the mean final in-hospital stay was 15 days (SD 21); and 20% died within two days of admission. Most patients (65%) had two or three family members involved in informal care during the last 24 hours.

The relatives participating in the study had a mean age of 56 years (SD 13), and 94% reported to be in moderate to (very) good health. Most of them were women (64%) and were the patient's spouse (42%) or child (in-law) (37%). In 88% of cases, they had been involved in informal care of the patient during the last 24 hours.

### Quality of Dying

The mean overall QOD score was 6.3 (SD 2.7; range 0–10; Figure 1).

### Symptoms and Death Preparation

Relatives reported that patients had suffered from a mean of five of 14 physical symptoms (SD 3.9) with moderate-severe intensity in the last 24 hours (Table 2). Most prevalent of the symptoms were dry mouth, decreased consciousness, fatigue, and dyspnea. Of patients with decreased consciousness in the final 24 hours ( $n = 120$ ), 80% already had decreased consciousness three days before death. Of the eight psychological symptoms studied, patients had suffered from a mean of 2 (SD 2.6) symptoms with moderate-severe intensity, of which feelings of powerlessness, sadness, anxiety, and worrying were most prevalent. In 23%–37%, relatives did not have insight into the patient's psychological symptoms, which was partly related to patients' decreased consciousness. In 37%, relatives reported that patients had been at peace with their imminent death. During

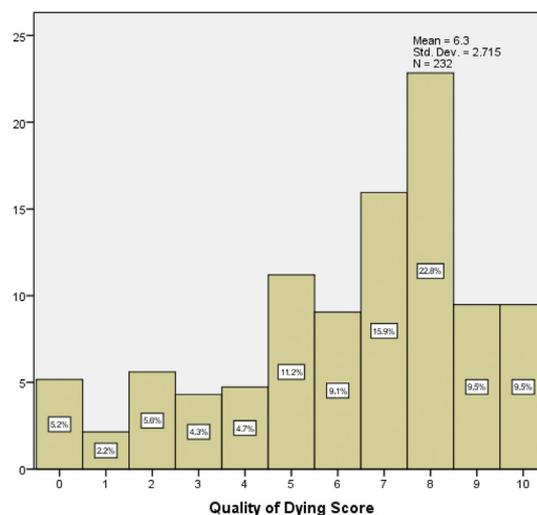


Fig. 1. Distribution of QOD scores.

the last month of life, 52% of all patients were reported to have discussed their preferences for medical treatment at the EOL (Table 3). In 31%, patients had discussed preferences with a physician, typically a general practitioner. Thirty-one percent of patients had indicated their preferred place of death: 20% preferred to die at home, 6% in hospital, and 5% in another setting.

In 26%, relatives reported that patients had known that their death was imminent, that is, likely to occur within a few days, and 39% of patients had been able to say good-bye to their family. Of the relatives, 49% had been aware of patients' imminent death. Two-thirds (64%) of the relatives reported that they had been informed by a physician on the patient's approaching death. In cases of decreased consciousness, relatives were more likely to be aware of imminent death and to be informed by the physician. Half of the relatives (50%) had said good-bye to the patient, and in 77%, at least one relative had been present at the moment of death.

### Experiences With Care

According to relatives, 42% of the patients had been sufficiently involved in medical decision making (Table 4). Relatives evaluated their own participation in medical decision making as sufficient in 70%, and 78% had received enough information about the patient's disease status and treatment options.

In 53% of cases, patients' symptoms and problems in the last 24 hours had been sufficiently alleviated according to relatives, and in 75%, they felt physicians had made enough effort trying to control symptoms. In 59%, the level of social and emotional support was sufficient, such as support in resolving practical problems, accepting the imminence of death, and in preparing to say good-bye. In 63%, relatives felt that

Table 2  
Physical, Psychological, Social, and Spiritual Experiences: Prevalence in the Last 24 Hours Before Death ( $n = 249$ )

Symptoms	Moderate-Severe		None-Mild		Don't Know		Missing					
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%				
<b>Physical</b>												
<i>Pain</i>	92	37	76	31	47	19	34	14				
<i>Dyspnea</i>	113	45	72	29	24	10	40	16				
<i>Coughing</i>	64	26	113	45	26	10	46	19				
<i>Death rattle</i>	89	36	90	36	26	10	44	18				
<i>Difficulty sleeping</i>	57	23	99	40	45	18	48	19				
<i>Fatigue</i>	115	46	48	19	46	19	40	16				
<i>Dry mouth</i>	128	51	38	15	44	18	39	16				
<i>Lack of appetite</i>	105	42	36	15	55	22	53	21				
<i>Nausea</i>	39	16	83	33	73	29	54	22				
<i>Swallowing problems</i>	97	39	56	23	46	19	50	20				
<i>Constipation</i>	63	25	55	22	82	33	49	20				
<i>Decreased consciousness</i>	120	48	71	29	17	7	41	17				
<i>Confusion</i>	74	30	84	34	43	17	48	19				
<i>Agitation</i>	95	38	76	31	32	13	49	20				
Total number of physical symptoms, mean (SD)	5.0 (3.9)											
<b>Psychological</b>												
<i>Anxiety</i>	69	28	60	24	71	29	49	20				
<i>Loneliness</i>	39	16	76	31	84	34	50	20				
<i>Dependency</i>	54	22	85	34	58	23	52	21				
<i>Tense</i>	56	23	68	27	72	29	53	21				
<i>Worrying</i>	65	26	58	23	76	31	50	20				
<i>Sadness</i>	75	30	54	22	72	29	48	19				
<i>Feelings of powerlessness</i>	81	33	47	19	70	28	50	20				
<i>Depressed mood</i>	52	21	54	22	92	37	51	21				
Total number of psychological symptoms, mean (SD)	2.0 (2.6)											
Total number of physical and psychological symptoms, mean (SD)	7.0 (5.8)											
					Don't Know		Missing					
					Yes		No					
					<i>n</i> %		<i>n</i> %					
					<i>n</i> %		<i>n</i> %					
<b>Social and Spiritual Experiences</b>												
<i>Patient was at peace with imminent death</i>					93	37	51	21	7	39	8	3
Patient had practical problems during last days of life (e.g., with finances or care for family)					43	17	187	75	15	6	4	2
Patient needed relatives' attendance or support					140	56	46	19	57	23	6	2
Need of attendance or support was fulfilled					133	53	6	2	15	6	95	40

No = no and more or less/sometimes.

Variables related to QOD score in univariate regression analysis are given in italics, adjusted for patient marital status and relative age.

the patient had sufficiently been regarded as a human being and in 70% that enough attention had been paid to hospital facilities, such as privacy and opportunities for having meals for the relatives.

### Explaining Overall QOD

Univariate analysis showed that of all the general characteristics of patients and relatives, living alone until final admission and a higher age of the relative were significantly associated with a higher QOD score. All simple regression analyses were controlled for these two characteristics.

Of all symptoms and problems, agitation, anxiety, and not being at peace with imminent death were most strongly related to QOD scores ( $R^2$  0.09, 0.11, and 0.08, respectively). Relatives being informed about patients' impending death ( $R^2$  0.11) and about patients' condition ( $R^2$  0.08) and relatives' opportunity to participate in decision making ( $R^2$  0.11) also were related to the QOD scores. The degree to which

relatives felt that physicians had made sufficient efforts to alleviate problems and symptoms in the last 24 hours was most strongly related to QOD ( $R^2$  0.14). In total, 37 variables were identified explaining part of the variation in QOD scores, and these are presented in italic in the tables.

### Identification of Relevant Domains Affecting QOD

All 37 variables, except the two case characteristics, were analyzed in two principal component analyses. Thirteen physical and psychological symptoms were combined in the 1st analysis. The Kaiser-Meyer-Olkin (KMO) measure of sample adequacy was 0.88 ( $P = 0.00$ ), which is considered high. The resulting rotated component matrix (varimax) had two components, which could be labeled as physical and psychological experiences ( $R^2$  0.54; Table 5, Domains 2 and 3).

The remaining 22 variables were combined in the 2nd analysis, with a KMO of 0.78 ( $P = 0.00$ ), which is considered good. This rotated component matrix

Table 3  
Life Closure/Death Preparation and Circumstances of Death (n = 249)

Patients	n <sup>a</sup>	% <sup>b</sup>
<i>Patient had discussed preferences for medical treatment at EOL</i>		
Yes	129	52
No	110	44
<i>Patient had discussed preferences for medical treatment at the EOL with a physician</i>		
Yes	77	31
No	172	69
<i>Patient had discussed preferences for place of death</i>		
Yes, preference for hospital	16	6
Yes, other preference	61	25
No, not discussed	159	64
Don't know	7	3
<i>Patient was aware of imminent death</i>		
Yes	65	26
No	135	54
Don't know	43	17
<i>Patient was able to say good-bye</i>		
Yes	96	39
No	132	53
Don't know	16	6
<i>Relative was aware of imminent death</i>		
Yes	121	49
No	119	48
Don't know	4	2
<i>Relative was informed of imminent death</i>		
Yes	160	64
No	81	33
Don't know	0	0
<i>Relative said good-bye to patient</i>		
Yes	125	50
No	121	49
Don't know	0	0
<i>Relative was present at moment of death</i>		
Yes	190	77
No	57	23
<i>In hindsight, the hospital was right place of death</i>		
Yes	131	53
No	98	39
Don't know	11	4
<i>Sufficient attention for preferred rituals at moment of death</i>		
Yes	110	44
No	23	9
Don't know	73	29

No = no and more or less/sometimes.

Variables related to QOD score in univariate regression analysis are given in italics, adjusted for patient marital status and relative age.

<sup>a</sup>Actual sample size may vary depending on missing values.

<sup>b</sup>Percentages may not add up to 100 because of missing values.

had six components, which could be labeled as “acceptance of imminent death,” “medical care/symptom management,” “preparation on and circumstances of dying,” “shared decision making,” “personalized care,” and “supportive care/care for relatives” ( $R^2$  0.62; Table 5, Domains 4–9).

For each domain, parameters were entered in multivariate linear regression models to assess the association between the identified domains and overall QOD (Table 5). All domains were significantly associated with QOD, with  $R^2$  being 0.02 for shared decision making, up to 0.22 for medical care. When we combined all domains in one regression analysis, the model explained 34% of the variation in QOD scores.

## Discussion

This study provides a comprehensive and detailed insight into what happens and what matters for patients dying in the hospital, according to bereaved relatives. Bereaved relatives rated QOD, in non-intensive care wards of a large university hospital, on average 6.3, which might be considered as sufficient, according to a widely used scoring system in The Netherlands, but their scores largely varied. The multidimensionality of QOD was confirmed, and we found a crucial impact of several characteristics of EOL care. When caring for terminally ill patients, health care professionals need skills to relieve symptoms and to recognize worsening of the patient's condition. These skills need to be combined with demonstration of awareness and attentiveness regarding individual patient and relative needs and adequate communication about prognosis, medical decisions, and patient and relative preferences.

### Strengths and Limitations of the Study

A major strength of this study is the comprehensive assessment of multiple dimensions of QOD and the thorough analysis of relationships between these dimensions and the overall score of QOD. As a result, to our knowledge, this is the 1st study explaining one-third of the aspects determining QOD in the hospital. QOD appeared to be strongly affected by medical care and staff attentiveness, and these results may contribute to the debate on QOD and quality of care for the dying, in the scientific literature and in society.<sup>31–34</sup>

One limitation of the study is that it was performed in one hospital, and although it was a large hospital with 18 different participating wards, this might diminish the generalizability of our results. The response rate of 51%, however, was fair when compared with the response rate of 35% in a comparable postal self-administered questionnaire study among bereaved relatives in the U.K.,<sup>35</sup> and patients' age, gender, duration of last admission, and type of wards were similarly distributed among included and nonincluded cases. A 2nd limitation is that we did not assess QOD using a previously studied questionnaire, such as the QODD, which might decrease the opportunity for comparison with other studies. We performed a retrospective study among all in-hospital deaths during 21 months, which decreases possible selection bias, but implies the impossibility of interviewing patients and the risk of recall bias.<sup>19,20</sup> The information on QOD was provided by relatives, and as such, our results do not reflect care as provided but care as perceived and remembered by relatives.

Table 4  
Nature of Health Care and Evaluation of Processes of Hospital EOL Care (n = 249)

Patients	n <sup>a</sup>	%
<i>In the last 24 hours, patient participated sufficiently in decision making on medical treatment</i>		
Yes	105	42
No	70	28
Don't know	49	20
<i>In the last 24 hours, patient participated sufficiently in decision making on nursing care</i>		
Yes	107	43
No	61	25
Don't know	50	20
<i>In the last 24 hours, relative participated sufficiently in decision making on medical treatment</i>		
Yes	175	70
No	44	18
Don't know	15	6
<i>In the last 24 hours, relative participated sufficiently in decision making on nursing care</i>		
Yes	170	68
No	32	13
Don't know	22	9
<i>Relative was informed sufficiently about situation, condition, and care</i>		
Yes	194	78
No (too little)	41	17
No (too much)	3	1
<i>Efforts to alleviate symptoms and problems last 24 hours before death were sufficient</i>		
Yes	187	75
No	40	16
Don't know	9	4
<i>Nursing care last 24 hours before death was sufficient</i>		
Yes	200	80
No	30	12
Don't know	5	2
<i>Social and spiritual support last 24 hours before death was sufficient</i>		
Yes	146	59
No	69	28
Don't know	16	6
<i>Symptoms were sufficiently alleviated in last 24 hours</i>		
Yes	131	53
No	59	24
Don't know	42	17
<i>Opportunity to discuss personal or religious preferences was sufficient</i>		
Yes	138	55
No	36	15
Don't know	54	22
<i>Attention to preferred rituals at the moment of death was sufficient</i>		
Yes	133	53
No	28	11
Don't know	69	28
<i>Affirmation of the patient as a whole person was sufficient</i>		
Yes	156	63
No	53	21
Don't know	25	10
<i>Attention to hospital facilities and wishes of patient and relative was sufficient</i>		
Yes	174	70
No	41	16
Don't know	19	8
<i>Effort to make last days of life tolerable for the patient was sufficient</i>		
Yes	140	56
No	44	18
Don't know	53	21

(Continued)

Table 4  
Continued

Patients	n <sup>a</sup>	%
<i>Effort to make the last days tolerable for relatives was sufficient</i>		
Yes	154	62
No	39	16
Don't know	39	16

No = no and more or less/sometimes.

Variables related to QOD score in univariate regression analysis are given in italics, adjusted for patient marital status and relative age.

<sup>a</sup>n may not add up to the total and percentages may not add up to 100 because of missing values.

### Main Findings and Comparison With Other Studies

In a randomized controlled trial on the Liverpool Care Pathway, Costantini et al.<sup>36</sup> recently described EOL care for cancer patients in Italian hospitals and found some similarities. The mean score for the quality of care in control wards in Italy was 63 on a 0–100 scale, which might be considered comparable with the mean score of 6.3 on a 0–10 scale we found for QOD. Findings on the presence of pain, dyspnea, and nausea in the dying phase also seem to be comparable. Furthermore, in both studies, relatives were relatively dissatisfied about the emotional support they had received. In our study, many patients suffered from multiple symptoms during the last 24 hours. In 53% of all cases, relatives indicated that symptoms were sufficiently alleviated. These findings are comparable with those reported elsewhere.<sup>8,36–41</sup> Relatives frequently reported not to know whether the patient suffered from psychological problems, which could partly be explained by patients' decreased consciousness. We did not find social experiences that were related to QOD scores.

Six physical symptoms explained 9% of the variation in QOD scores, whereas efforts made by staff to alleviate these symptoms explained 14%. Relatives probably tend to accept unrelieved symptoms, as long as physicians demonstrate that they are consciously addressing the patient's problems and needs. Relatives' trust that the physician does his utmost in EOL care has previously been found to be an important attribute of a good QOD.<sup>42,43</sup>

Although almost all participating relatives were involved in care of the patient during the last days of life, and 64% had been told that the patient's death was imminent; only half of them had foreseen that the patient would die at short notice. Patients' decreased consciousness during the last days of life increased the likelihood that relatives had foreseen death. The relatively common lack of awareness of the imminence of death might be influenced by the

Table 5  
**Domains of Dying and Care Explaining Variance of Quality of Dying Score**

Theme Variables	B <sup>a</sup> (SE)	P-value	R <sup>2b</sup>
General characteristics			
Marital status	1.13 (0.35)	0.00	
Age relative	0.04 (0.01)	0.00	
General characteristics	1.01 (0.25)	0.00	0.06
Physical experiences			
Pain	-0.24 (0.41)	0.55	
Trouble sleeping	-0.74 (0.46)	0.11	
Dry mouth	-0.01 (0.42)	0.99	
Nausea	-0.39 (0.49)	0.42	
Fatigue	-0.24 (0.44)	0.58	
Agitation	-0.93 (0.41)	0.03	
Physical experiences	1.00 (0.23)	0.00	0.09
Psychological experiences			
Anxiety	-0.48 (0.59)	0.42	
Loneliness	-0.28 (0.60)	0.64	
Tenseness	-0.89 (0.57)	0.12	
Sadness	-0.98 (0.62)	0.12	
Powerlessness	0.52 (0.61)	0.39	
Worrying	-0.14 (0.51)	0.78	
Depressive mood	0.41 (0.67)	0.54	
Psychological experiences	1.00 (0.25)	0.00	0.08
Acceptance of imminent death			
At peace with imminent death	1.22 (0.38)	0.00	
Patient was aware of imminent death	0.17 (0.43)	0.70	
Acceptance	1.00 (0.28)		0.05
Medical care/symptom management			
Symptoms alleviated	0.51 (0.37)	0.17	
Efforts to alleviate symptoms and problems in final 24 hours	1.67 (0.43)	0.00	
Relative was informed on imminence of death	1.25 (0.36)	0.00	
Hospital right place of death in hindsight	0.63 (0.33)	0.06	
Medical care/symptom management	1.00 (0.12)	0.01	0.22
Preparation on/circumstances of death			
Relative was aware of imminent death	0.09 (0.36)	0.81	
Attention to hospital facilities and wishes of patient and relatives	1.37 (0.41)	0.00	
Relative was present at moment of death	-0.01 (0.44)	0.98	
Relative said good-bye	0.88 (0.45)	0.05	
Patient said good-byes	0.14 (0.44)	0.72	
Circumstances of death	1.00 (0.19)	0.00	0.11
Shared decision making			
Patient participated in nursing care decisions	0.92 (0.60)	0.12	
Patient participated in medical decisions	-0.04 (0.61)	0.95	
Shared decision making	1.00 (0.40)	0.01	0.02
Personalized care			
Affirmation of the patient as a person	1.27 (0.41)	0.00	
Attention to preferred rituals at moment of death	0.30 (0.37)	0.42	
Opportunities to discuss personal or religious preferences	0.69 (0.38)	0.07	
Discussed preferences on EOL treatment	0.25 (0.34)	0.46	
Social and spiritual support last 24 hours	0.75 (0.39)	0.06	
Personalized care	1.00 (0.15)	0.00	0.16
Supportive care/care for relatives			
Relative participated in nursing care decisions	0.11 (0.66)	0.86	
Relative informed about condition and care	1.42 (0.58)	0.01	
Relative participated in medical decisions	1.16 (0.59)	0.05	
Nursing care in final 24 hours	0.38 (0.52)	0.46	
Supportive care/care for relatives	1.00 (0.16)	0.00	0.15
Total of domains	0.35 (0.03)	0.00	0.34

EOL = end of life.

<sup>a</sup>B = unstandardized regression coefficient, expressing the strength of the association relation between a variable and QOD. Total domains on QOD score = sum of (domains × unstandardized coefficient [B]): (general characteristics × 1.01) + (physical exp × 1.00) + (psychological exp × 1.00) + ....

<sup>b</sup>Adjusted R<sup>2</sup>.

fact that in The Netherlands, patients are generally only admitted to the hospital when they have a chance of recovery or prolongation of life; only one-third of all deaths occur in the hospital. For patients who are expected to die within weeks or days, care is preferably

provided by home care organizations or hospices. In the hospital setting, where care is typically focused on prolonging life, it is often difficult to identify in advance those patients who are unlikely to recover from a worsening condition.<sup>44</sup> However, in a parallel

study in the same population, physicians had been aware of the patient's imminent death in 79% of cases.<sup>45</sup> The difference between physician's awareness and relative's and patient's awareness might be correlated with problematic communication but also to variation in the interpretation of what "imminent death" entails.<sup>46,47</sup>

Whether and how physicians actually informed relatives about the patient's imminent death was not assessed and might differ from relatives' reports.<sup>48</sup> It has previously been shown that communication between physicians and patients or relatives about a poor prognosis and imminent death is often problematic.<sup>7,12,49,50</sup> Nevertheless, families of severely ill patients have been shown to need prognostic information, especially if the prognosis is poor. Respect, sensitivity, compassion, and frequent communication have been identified as important conditions to support such communication.<sup>51–53</sup> Relatives in our study reported that only 26% of the patients had been fully aware of imminent death. Patient awareness of and being at peace with approaching death were correlated with higher QOD scores, which also has been found elsewhere.<sup>46</sup>

In 77% of all studied cases, patients died in the presence of family, which was more than that reported in studies in hospitals in New Zealand and France, where 60% and 34% of deceased patients, respectively, died with family present.<sup>3,9</sup> Presence at the moment of death was not strongly related to QOD; relatives gave more weight to saying good-bye.

We found that attentiveness to relatives affected QOD experiences. In EOL care, collaboration between relatives and professional staff is crucial, for example, regarding recognition of and communication about patient problems, decision making, and the organization of care.

Our study confirmed the multidimensionality of QOD. We found an impact of symptom burden, staff attentiveness to the needs of patients and their relatives, adequate information and communication, and acceptance of imminent death. The explained variation of 34% of the QOD scores still leaves us with a large proportion of unexplained variance. It is likely that factors such as personality traits of patients and relatives, cultural and ethnic factors, patients' quality of life during the phase preceding the dying phase, and perceptions of what a good death entails may also contribute to the explanation of QOD ratings.<sup>13,23,42,54</sup> Our findings confirmed the results of Zhang et al.,<sup>13</sup> who could explain 19% of the variation in quality of life scores of cancer patients and demonstrated the importance of religious care and of the formation of a "therapeutic alliance" between the oncologist and the patient.<sup>13</sup>

Nevertheless, for a better understanding of factors explaining the variance in QOD, more observational research is needed, in addition to experimental studies on interventions to improve EOL care in the hospital.

### **Disclosures and Acknowledgments**

This study was financially supported by a grant from the Erasmus MC Medical Research Committee (grant number 2007-7208) and the Tom and Josephine Rijckes Legacy Foundation; neither had any involvement in the study or publication. All authors declare that they have no competing interests. The study was conducted independent from the funders. All authors have full access to all the data (including statistical reports and tables) in the study and take responsibility for the integrity of the data and the accuracy of the analysis.

The authors thank the hospital Patient Council for their critical advice and support.

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