

*Original Article*

# End-of-Life Care in Italian Hospitals: Quality of and Satisfaction With Care From the Caregivers' Point of View—Results from the Italian Survey of the Dying of Cancer

Monica Beccaro, MA, Augusto Caraceni, MD, and Massimo Costantini, MD,  
on behalf of the ISDOC Study Group

*Regional Palliative Care Network (M.B., M.C.), National Cancer Research Institute, Genoa; and  
Palliative Care, Pain Therapy, Rehabilitation Unit (A.C.), Fondazione IRCCS Istituto Nazionale dei  
Tumori, Milan, Italy*

---

## Abstract

**Context.** A number of studies have highlighted the poor quality of end-of-life (EOL) care provided in hospital settings, leading to a reduction in the quality of EOL care and increase in patient and caregiver dissatisfaction levels.

**Objectives.** The aims of this study were the evaluation of the prevalence of major symptoms, treatment, outcomes, information, and care provided to dying cancer patients in Italian hospitals; and an analysis of clinical and socio-demographic factors associated with caregiver satisfaction with the health care provided.

**Methods.** This is a mortality follow-back survey of 2,000 cancer deaths representative of the country. Caregivers were interviewed about patients' experiences by using a tailored version of the View of Informal Carers—Evaluation of Services questionnaire.

**Results.** Valid interviews were obtained for 84% ( $n = 364$ ) of the cancer patients who died in hospital. Most Italian cancer patients dying in hospital suffered from a number of untreated or poorly treated symptoms, and only a few reported an acceptable control over physical suffering. Moreover, only two-thirds of patients and one-third of caregivers received basic information on therapies and care. About one-third of the caregivers expressed dissatisfaction with the health care received. The probability of being satisfied was more likely for caregivers of patients living in the north of Italy; caregivers of patients who had not experienced or were only slightly distressed by fatigue; and caregivers who were generally satisfied with hospital facilities and when the health care professionals had provided appropriate information to both patients and caregivers.

---

See [Appendix](#) for members of the ISDOC Study Group.

This study was funded by the Italian Ministry of Health (Progetto di Ricerca Finalizzata 2001–2003).

*Address correspondence to:* Monica Beccaro, MA, Regional Palliative Care Network, National Cancer Research Institute, Largo R. Benzi 10, 16132, Genoa, Italy. E-mail: [monica.beccaro@istge.it](mailto:monica.beccaro@istge.it)

*Accepted for publication:* November 5, 2009.

**Conclusion.** This study revealed poor quality of EOL care in Italian hospitals, with almost one-third of the caregivers expressing their clear dissatisfaction. A national policy is, therefore, urgently called for to improve the quality of EOL care in Italian hospitals. *J Pain Symptom Manage* 2010;39:1003–1015. © 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

### Key Words

*End-of-life care, caregiver, satisfaction, cancer patients, postbereavement survey*

## Introduction

Despite the worldwide development of palliative care services and programs, in many Western countries, 50% of all deaths occur in hospital acute care units.<sup>1–4</sup> A number of studies have highlighted the poor quality of end-of-life (EOL) care provided in hospital settings: Most dying patients receive inappropriate care because of inadequate evaluation and poor treatment of physical suffering, and patient and family emotional, spiritual, and communication needs are unmet.<sup>5–12</sup> This leads to a reduction in the quality of EOL care and to an increase in patient and caregiver dissatisfaction levels.<sup>13–15</sup>

A few postbereavement surveys identified the determinants of care dissatisfaction as lack of information and poor communication between health care professionals and patients and families; physical suffering; and scarce consideration of the patient's emotional and spiritual needs.<sup>7,16,17</sup> A survey carried out in 2005 in 40 Italian hospitals showed that acute inpatient institutions in Italy ineffectually address the needs of dying patients.<sup>9</sup> A curative approach involving aggressive, life-prolonging interventions and overtreatment was sustained even in patients who were close to death. To date, there are no national data available concerning the type and quality of EOL care provided to hospitalized dying cancer patients and the satisfaction expressed by caregivers regarding treatment and care received.

The Italian Survey of the Dying of Cancer (ISDOC) is a mortality follow-back survey conducted in a stratified random sample of Italian cancer deaths. Information regarding the last three months of life was obtained from caregivers interviewed after the patient's death, using the View of Informal Carers—Evaluation of Services (VOICES) questionnaire.<sup>18</sup> ISDOC aimed at providing a national appraisal of

the EOL care experiences of dying cancer patients in all settings of care. This article reports the results from specific sections of the interview, which focus on the type and quality of care and treatments provided during the dying patient's last hospitalization and the satisfaction expressed by their caregivers. The analysis of this subsample of cancer patients who died in Italian hospitals after a hospital stay of more than 24 hours was specifically aimed at 1) comparing the characteristics of dying cancer patients in Italian hospitals with those of all Italian cancer deaths; 2) estimating the prevalence of major symptoms, the treatment provided, and the positive outcome of the treatment of cancer patients during their last hospitalization; 3) estimating the ratio of cancer patients and their caregivers who received appropriate information and support by medical staff during the last hospital stay; 4) estimating the level of satisfaction expressed by caregivers; and 5) analyzing which clinical and sociodemographic factors were associated with care satisfaction.

## Methods

### *The Italian Survey of the Dying of Cancer*

A two-stage probability sample was used to assess the EOL experiences of approximately 160,000 annual cancer deaths in Italy. In the first stage, 30 of the 197 existing Local Health Districts (LHD) were randomly selected. In the second stage, a fixed proportion of adult cancer deaths (aged 18 years or older) was drawn from each LHD, constituting a sample of 2,000 death certificates of cancer patients who had died between March 2002 and June 2003.<sup>19</sup>

For each deceased patient, a nonprofessional caregiver, defined as the closest and best-informed person in the last three months of

the patient's life, was identified by looking at clinical records or by contacting general practitioners. For patients who died without a non-professional caregiver, the health professional closest to the patient was identified. Identified caregivers were then contacted by a trained interviewer, both by letter and phone, to obtain consent to be interviewed.

A nonprofessional caregiver was identified for 92.1% of deceased patients ( $n = 1,843$ ). A professional caregiver was identified for 2.9% of the deceased patients ( $n = 57$ ). Research was unsuccessful for 100 patients (5.0%). An interview was conducted with 1,289 (67.8%) of the identified caregivers (1,247 nonprofessional and 42 professional) at a median time of 234 days after the patients' death (range 103–374). Of the remaining 611 noninterviewed caregivers, 161 (8.5%) could not be located, 383 (20.1%) refused to be interviewed, 38 (2.0%) were too ill to participate, and 7 (0.4%) had died. Because of staff errors during planning, 22 interviews (1.1%) were not carried out. Finally, six patients whose death could not strictly be attributed to cancer and 12 patients who did not reach the terminal phase of disease were excluded from all the statistical analyses.

Interviews were conducted less frequently among patients who died in the hospital (odds ratio [OR] = 0.6; 95% confidence interval [CI] = 0.4–0.7) than those who died at home and among patients with lower levels of schooling. No significant differences by age, gender, marital status, and primary tumor, were observed. More information regarding the methodology of the survey has been published in a previous article.<sup>19</sup>

The study design was approved by the Ethics Committee of the National Cancer Institute of Genoa, and the Italian Data Protection Commission was notified of both the study design and procedures, according to the Italian law regulating the use and processing of health data.

#### *Data Collection*

Interviews were conducted using an adapted version of the VOICES questionnaire.<sup>18</sup> This questionnaire is the short version of the interview schedule used in the Regional Study of Care for the Dying.<sup>20</sup> The Italian translation of the questionnaire was previously tested in

a sample of caregivers of deceased acquired immunodeficiency syndrome patients in Genoa.<sup>21</sup> The interview covered the last three months of life and evaluated a number of possible problems experienced by the patients and their families.

The first part of the VOICES questionnaire includes four sections for each of the four possible settings of care: home, nursing home, hospital, and hospice. The hospital section explored the following: 1) if the patient had died in hospital, the last inpatient hospital stay of more than 24 hours; and 2) if the patient had died elsewhere, the longer periods of inpatient hospitalization. Patients with a hospital stay of less than 24 hours were excluded because the time was not sufficient to obtain valuable information from caregivers.

The hospital section includes 35 questions overall. The results from two questions exploring treatments not provided or judged unnecessary and from four questions exploring quality of care received from social and health professionals were excluded from the analyses because of the high numbers of missing information. The question about the involvement of a pain service in care has already been investigated and results reported in a previously published article.<sup>22</sup> The second part of the VOICES questionnaire includes questions exploring the domains independent of the setting of care. The two questions referring to communication with health care professionals before and after the patient's death have been included in the analyses.

#### *Statistical Methods*

All analyses were performed using SUDAAN version 9.0.1 (Research Triangle Institute, Research Triangle Park, NC). This software, for the point and standard error (SE) statistics estimation, takes into account four characteristics of complex survey data: the unequal probability selection of observations, the clustering of observations, stratification, and non-response. Sampling weights were introduced to obtain unbiased weighted point and SE estimates of the target population.

The differences in the distribution of categorical variables (gender and marital status, preferred place of death, disclosure of diagnosis, disclosure of prognosis, primary tumor, and caregiver relationship) were tested by means

of Chi-squared test for heterogeneity. The differences in the distribution of ordinal variables (age at death, education, interval since diagnosis, duration of non-self-sufficiency for everyday tasks, number of cohabitants, age and education of the caregivers) were tested by means of Chi-squared test for trend.

Multivariate logistic regression models were applied to examine the associations between patient and caregiver characteristics (the independent variables) and the overall satisfaction expressed by the caregivers concerning treatment and care received during the patient's last hospital stay. For this analysis, the 4-point Likert scale was transformed into a binary variable: satisfied (excellent or good care) and not satisfied (fair or poor care). Patient and caregiver characteristics were all included in the logistic regression model. Variables with  $P > 0.10$  were removed from the model by means of a step-down procedure to obtain the final model. For the variables included in the final logistic model, the strength of the association was estimated in terms of OR, the ratio of the odds of caregiver and patient satisfaction in a given category to the corresponding odds in a reference category. In the model, the Chi-squared test statistics for heterogeneity and trend were used to test the associations between the dependent variable and the independent categorical and ordinal variables, respectively.

## Results

### Study Sample

Of 1,271 Italian cancer patients in the ISDOC sample, 477 (34.6%) had died while hospitalized (Fig. 1). Of those, 42 were excluded from the analyses because hospitalization lasted less than 24 hours. Of the remaining 435 cancer patients, 71 were excluded because of staff errors. Valid interviews were obtained for 83.7% ( $n = 364$ ) of the deceased cancer patients with a last inpatient hospital stay of more than 24 hours (76.3% of total).

### Characteristics of Dying Cancer Patients in Italian Hospitals Compared With All Italian Cancer Deaths

Overall, the estimated proportion of cancer patients who died in hospital in Italy was 34.6%

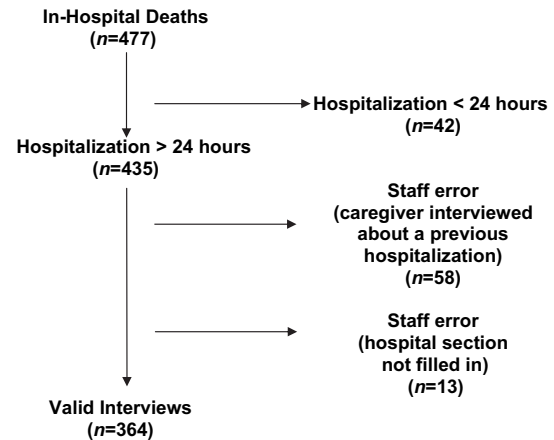


Fig. 1. Flowchart of the study sample.

(95% CI = 29.0–40.6) (Table 1). Younger cancer patients died more frequently in hospital compared with older patients ( $P = 0.02$ ). Cancer patients living in the northern regions of Italy were more likely to die in hospital compared with those living in the central and southern regions ( $P < 0.001$ ). A higher proportion of patients who preferred to die in hospital had a greater likelihood to do so (90.9%) compared with other places of death ( $P < 0.01$ ). The probability of dying in hospital was unevenly distributed according to the time interval from diagnosis to death ( $P = 0.03$ ). Patients informed about their diagnosis and prognosis were more likely to die in hospital compared with other places of death ( $P = 0.01$  and  $P < 0.01$ , respectively). There were no significant differences in patient gender ( $P = 0.34$ ) and education level ( $P = 0.55$ ), marital status ( $P = 0.74$ ), type of tumor ( $P = 0.24$ ), duration of non-self-sufficiency for everyday tasks ( $P = 0.26$ ), number of cohabitants ( $P = 0.09$ ), caregiver's relationship ( $P = 0.51$ ), caregiver's age ( $P = 0.31$ ), caregiver's gender ( $P = 0.95$ ), and caregiver's education level ( $P = 0.18$ ).

### Prevalence of Major Symptoms During the Last Inpatient Hospital Stay

According to informal caregiver reports, pain was experienced by 80.4% of dying cancer patients during their last inpatient hospital stay (Table 2). At least 65.5% of the patients experienced very distressing pain. Among the other symptoms, the most prevalent was

**Table 1**  
**Characteristics of Dying Cancer Patients in Italian Hospitals Compared With Overall Italian Cancer Deaths**

Characteristics	All Deaths ( <i>n</i> = 1,271)		In-Hospital Deaths ( <i>n</i> = 477)	
	<i>n</i>	% <sup>a</sup>	95% CI <sup>a</sup>	
<i>The patient</i>				
Age at death (years) ( <i>P</i> = 0.018)				
18–54	83	44.8	35.0–55.0	
55–64	164	45.1	35.0–55.8	
65–74	359	36.3	28.1–45.4	
75–84	438	28.5	22.6–35.4	
85+	227	32.5	24.8–41.3	
Gender ( <i>P</i> = 0.337)				
Male	713	35.6	29.3–42.4	
Female	558	33.2	27.7–39.2	
Education (years) ( <i>P</i> = 0.554)				
≤5	833	33.5	27.4–40.1	
6–9	228	35.0	27.2–43.7	
10+	208	39.1	30.0–49.1	
Marital status ( <i>P</i> = 0.742)				
Married	743	35.0	29.8–41.7	
Single <sup>b</sup>	519	33.9	27.4–41.1	
Region of residence ( <i>P</i> < 0.001)				
Northern Italy	813	49.6	43.7–55.5	
Central or southern Italy	458	18.2	12.0–26.8	
Preferred place of death ( <i>P</i> < 0.001)				
Home	930	24.7	19.4–30.9	
Hospital	56	90.9	79.1–96.3	
Nursing home	17	4.0	0.5–27.2	
Not known	268	63.0	55.0–70.4	
Disclosure of diagnosis ( <i>P</i> < 0.001)				
Informed	481	42.2	35.8–48.1	
Not informed	756	30.7	24.5–37.6	
Disclosure of prognosis ( <i>P</i> = 0.010)				
Informed	162	44.6	37.1–52.3	
Not informed	1,051	33.2	27.0–40.1	
<i>Type of disease</i>				
Primary tumor ( <i>P</i> = 0.238)				
Head and neck	28	46.3	29.2–64.4	
Digestive system	465	34.5	27.7–41.9	
Respiratory system	266	39.8	32.5–47.7	
Breast	125	32.3	24.9–40.7	
Genitourinary system	186	26.5	19.1–35.5	
Hematological	92	35.2	23.6–48.7	
Others and unspecified	109	34.7	23.4–48.1	
Months since diagnosis ( <i>P</i> = 0.025)				
1–3	250	47.7	37.1–58.5	
4–6	174	30.7	22.5–40.2	
7–12	221	35.9	28.9–43.6	
13–36	320	29.1	22.4–36.8	
>36	267	31.9	24.8–40.0	
Period of non-self-sufficiency for everyday tasks (days before death) ( <i>P</i> = 0.259)				
0–10	285	41.8	33.1–51.1	
11–30	331	35.5	27.2–44.8	
31–90	177	33.4	23.8–44.6	

(Continued)

**Table 1**  
**Continued**

Characteristics	All Deaths ( <i>n</i> = 1,271)		In-Hospital Deaths ( <i>n</i> = 477)	
	<i>n</i>	% <sup>a</sup>	95% CI <sup>a</sup>	
90+	465	30.6	24.0–38.1	
<i>The family</i> ( <i>P</i> = 0.089)				
Cohabitants				
None	183	37.3	28.8–46.7	
1	531	39.7	33.4–46.3	
2+	557	29.3	21.7–38.0	
Caregiver relationship ( <i>P</i> = 0.513)				
Spouse-partner	384	37.5	30.5–45.0	
Offspring	586	33.0	26.3–40.6	
Others	301	33.7	26.5–41.8	
Caregiver's age ( <i>P</i> = 0.308)				
18–44	337	33.0	24.1–43.3	
45–54	292	31.3	25.9–37.3	
55–64	272	37.8	30.1–46.3	
65–74	214	39.5	31.1–48.6	
75+	80	36.5	25.4–49.3	
Caregiver's gender ( <i>P</i> = 0.954)				
Male	387	34.4	27.5–42.1	
Female	884	34.6	28.7–41.0	
Caregiver's education (years) ( <i>P</i> = 0.181)				
≤5	345	40.6	31.7–50.1	
6–9	250	31.7	24.8–39.7	
10+	584	33.5	27.0–40.8	
Total	1,271	34.6	29.0–40.6	

<sup>a</sup>All percentages (95% CI) are weighted.<sup>b</sup>Including widowed, separated, and divorced.

fatigue (90.0%), with a proportion of very distressing symptom of 74.1%. Loss of appetite affected 79.4% of the patients; breathlessness, 61.6%; constipation, 55.7%; insomnia, 51.4%; and nausea, 38.6%. The proportions of patients with very distressing symptoms were as follows: loss of appetite, 57.2%; breathlessness, 44.6%; constipation, 38.5%; insomnia, 39.6%; and nausea, 28.0%.

Overall, only 2.9% of patients did not suffer from any symptoms during their last hospital stay; 24.4% were troubled by one to three symptoms; 45.5% experienced four or five symptoms; and 27.2% experienced six or seven symptoms. With reference to patients who were not troubled at all or who were troubled by one to seven very distressing symptoms, the proportions were as follows: 10.4% did not suffer from any very distressing symptom; 42.8% from one to three symptoms; 31.8% from four to five symptoms; and 15.0% from six to seven symptoms.

Table 2  
Prevalence of Major Symptoms of Dying Cancer Patients in Italy During Their Last Inpatient Hospital Stay

Symptom	Symptom Prevalence		Prevalence of Very Distressing Symptoms <sup>a</sup>	
	%	95% CI	%	95% CI
Pain	80.4	75.7–84.4	65.5	61.1–69.6
Fatigue	90.0	85.7–93.0	74.1	68.1–79.4
Nausea/vomiting	38.6	30.9–46.8	28.0	22.1–34.9
Loss of appetite	79.4	73.2–84.5	57.2	48.5–65.4
Constipation	55.7	47.0–64.0	38.5	31.0–46.5
Breathlessness	61.6	53.7–69.0	44.6	37.4–52.1
Insomnia	51.4	45.1–57.7	39.6	33.6–46.0
Absence of symptoms	2.9	1.5–5.8	10.4	7.8–13.8
1–3 symptoms	24.4	19.2–30.4	42.8	36.6–49.2
4–5 symptoms	45.5	41.3–49.7	31.8	26.1–38.2
6–7 symptoms	27.2	22.2–33.0	15.0	11.2–19.8

<sup>a</sup>Prevalence of very distressing symptoms equals the proportion of patients reported by the caregivers as experiencing the symptom, which distressed the patients “much or very much.”

#### Treatment Received for Seven Major Symptoms and Positive Outcome of Treatment During the Last Inpatient Hospital Stay

According to caregiver reports, overall, 77.9% of Italian cancer patients received treatment for pain during their last inpatient hospital stay; patients with very distressing pain received pain relief treatment more frequently (98.9% vs. 83.3%) compared with patients with only slightly distressing pain (Table 3). Among

the subgroup of patients who received treatment for pain, only 52.4% had their pain completely relieved all the time (49.7% with very distressing pain and 73.7% with slightly distressing pain).

Concerning other symptoms, treatment was administered to 81.9% of patients suffering from nausea, 80.7% from breathlessness, 78.9% from insomnia, 75.7% from constipation, 56.7% from fatigue, and 50.7% from loss

Table 3  
Treatment Received for Seven Major Symptoms and Positive Outcome of Treatment During the Last Inpatient Hospital Stay

Symptom	Slightly Distressing Symptom <sup>c</sup>		Very Distressing Symptom <sup>d</sup>		Sum of Patients With Symptom	
	%	95% CI	%	95% CI	%	95% CI
Treatment received for <sup>a</sup>						
Pain	83.3	65.3–93.0	98.9	97.2–99.6	77.9	73.2–81.9
Fatigue	48.1	31.1–65.5	58.5	48.3–67.9	56.7	46.4–66.4
Nausea/vomiting	73.9	53.0–87.7	85.2	70.9–93.1	81.9	68.6–90.4
Loss of appetite	38.9	28.3–50.6	54.9	43.2–66.1	50.7	40.4–61.0
Constipation	75.5	53.6–89.1	75.8	64.8–84.1	75.7	65.3–83.7
Breathlessness	57.8	39.0–74.6	87.7	80.3–92.5	80.7	72.2–87.2
Insomnia	75.8	50.1–90.7	79.9	67.2–88.5	78.9	67.5–87.1
Positive outcome for <sup>b</sup>						
Pain	73.7	51.6–88.0	49.7	41.0–58.4	52.4	43.9–60.8
Fatigue	10.2	3.9–24.1	8.5	3.8–18.0	8.8	4.3–16.9
Nausea/vomiting	28.6	15.5–46.8	17.5	9.4–30.1	20.3	13.3–29.9
Loss of appetite	24.2	11.7–43.5	3.9	1.1–13.1	7.9	4.0–15.3
Constipation	23.6	9.5–47.7	13.9	8.1–22.7	16.9	10.0–27.1
Breathlessness	25.0	11.2–46.7	18.6	12.9–26.0	19.6	14.1–26.6
Insomnia	31.3	15.4–53.2	14.3	6.8–27.6	18.1	10.7–28.9

<sup>a</sup>Analyses limited to the subgroups of patients with the symptom.

<sup>b</sup>Analyses limited to the subgroups of patients with the symptom who received treatment. Positive outcome for pain means that pain was controlled by treatment “completely, all or some of the time;” for the other symptoms, it means that they were controlled by treatment “much or very much.”

<sup>c</sup>Slightly distressing symptom equals the proportion of patients reported by the caregivers as experiencing the symptom, which distressed the patients “a little or not at all.”

<sup>d</sup>Very distressing symptom equals the proportion of patients reported by the caregivers as experiencing the symptom, which distressed the patients “much or very much.”

of appetite. For all symptoms, patients with very distressing symptoms received treatment more often (ranging from 87.7% for breathlessness to 54.9% for loss of appetite) compared with patients with slightly distressing symptoms (range from 75.8% for insomnia to 38.9% for loss of appetite).

Among the subgroup of patients with these symptoms, according to caregiver reports, only a negligible proportion had their symptoms controlled by treatment (ranging from 7.9% for loss of appetite and 20.3% for nausea). Furthermore, caregivers reported that positive outcomes for the treatment of all symptoms were inferior in patients with very distressing symptoms (ranging from 18.6% for breathlessness to 3.9% for loss of appetite) compared with the patients with slightly distressing symptoms (ranging from 28.6% for nausea to 10.2% for fatigue).

#### *Information and Support Provided by Health Care Professionals to Patients and Caregivers During the Last Inpatient Hospital Stay*

Caregivers reported that, during the last inpatient hospital stay, physicians provided information about the most appropriate treatments and care to only 29.9% patients (Table 4). In 74.0% of the cases, families received the necessary information concerning patient

Table 4

#### **Information and Support Provided by Health Professionals to the Patients and Caregivers During the Last Inpatient Hospital Stay**

Caregiver's Answer	%	95% CI
Did doctors give the patient all the information he/she needed to make decisions regarding the most appropriate treatments and care?		
Yes	29.9	22.1–39.2
Did doctors provide the caregiver with all the necessary information when making decisions about the patient's treatment?		
Yes	74.0	67.7–79.4
Did doctors give the caregiver any information about the patient's condition in an insensitive manner?		
No	82.0	77.3–86.0
At the time of death, did the medical staff inform the family about what was happening?		
Yes	69.0	61.6–75.4
Since the patient's death, has the caregiver talked to any health care staff about his/her feelings?		
Yes	18.1	13.5–24.0

treatment from physicians. In 82.0% of the cases, caregivers received information from physicians about the condition of the patient in a supportive and appropriate manner. In 69.0%, the physician had informed the caregiver of the imminence of the patient's death. After the patients' death, only 18.1% of the caregivers had the possibility to talk to a health care professional about their feelings.

#### *Caregiver Satisfaction With Care and Treatment Received During the Last Inpatient Hospital Stay*

Most caregivers reported that the hospital services, care provided by medical and nursing staff, and overall care were "excellent" or "good" (ranging from 67.5% for hospital services to 74.2% for physicians); less than one-third of caregivers expressed a negative evaluation of care provided to the patients during their last inpatient hospital stay (ranging from 22.4% for physicians to 30% for hospital services) (Table 5).

#### *Multivariate Logistic Regression Analyses of Determinants of Satisfaction Expressed by Informal Caregivers About the Overall Assistance Received During the Patient's Last Inpatient Hospital Stay*

According to caregiver reports, the probability of satisfaction with the health care provided during the last inpatient hospital stay was more likely for patients living in the north of Italy (OR = 3.30; 95% CI = 1.43–7.61) compared with patients living in the south (Table 6). This probability increased significantly for caregivers who were satisfied with the hospital services (OR = 15.58; 95% CI = 9.21–26.35). Treatment satisfaction was more likely to be expressed by the caregivers of patients who had not suffered, or had suffered slightly, from fatigue ( $P = 0.06$ ). The probability of being satisfied significantly increased when medical staff provided information about treatment both to patients and caregivers ( $P = 0.02$  and  $P < 0.01$ , respectively); when the caregivers were informed about the patient's condition appropriately ( $P < 0.01$ ); and when the caregiver was informed of the patient's imminent death ( $P = 0.01$ ).

Table 5  
Satisfaction Expressed by Caregivers About Care and Treatment Received During the Patient's Last Inpatient Hospital Stay

Caregiver's Answer	Hospital Services <sup>a</sup>	Physicians <sup>b</sup>	Nurses <sup>c</sup>	Overall <sup>d</sup>
	%	%	%	%
Excellent	12.5	24.1	21.5	19.2
Good	55.0	50.1	51.0	50.3
Fair	18.0	14.4	14.1	19.1
Poor	12.0	8.0	10.2	7.8
Unknown	2.5	3.4	3.2	3.7
Total	100	100	100	100

Caregivers were asked the following questions:

<sup>a</sup>During hospital admission, how would you rate the hospital services (i.e., food, bedroom, bath)?

<sup>b</sup>During hospital admission, how would you rate the assistance that the patient received from the medical staff?

<sup>c</sup>During hospital admission, how would you rate the assistance that the patient received from the nursing staff?

<sup>d</sup>During hospital admission, how would you rate the overall assistance that the patient received inside the hospital ward?

## Discussion

This is one of the few population-based surveys exploring the quality of EOL care provided to cancer patients and their caregivers during the last inpatient hospital stay.

According to informal caregiver reports, most cancer patients dying in Italian hospitals suffered from a number of untreated or poorly treated symptoms. Only a minority obtained acceptable treatment for their physical

Table 6  
Multivariate Logistic Regression Analyses of Determinants of Satisfaction Expressed by Informal Caregivers About the Overall Assistance Received During the Patient's Last Inpatient Hospital Stay

Independent Variables	Excellent or Good Overall Assistance <sup>a</sup>		
	OR	95% CI <sup>b</sup>	P-value
Place of residence			
Northern Italy	3.30	1.43–7.61	0.01
Central and southern Italy	Ref.		
Fatigue			
Absent or slightly distressing	1.75	0.97–3.19	0.06
Very distressing	Ref.		
Satisfaction with hospital services			
Fair or poor	Ref.		0.01
Excellent or good	15.58	9.21–26.35	
Information provided by health professionals			
To the patient regarding treatment			
No	Ref.		0.02
Yes	3.90	1.21–12.57	
To the caregiver regarding treatment			
No	Ref.		<0.01
Yes	5.92	2.24–15.66	
To the caregiver in an appropriate manner			
No	5.39	1.89–15.34	<0.01
Yes	Ref.		
To the caregiver about the imminence of death			
No	Ref.		0.01
Yes	2.41	1.22–4.76	

Ref. indicates reference category (Ref = 1).

<sup>a</sup>Caregivers were asked the following question: During hospital admission, how would you rate the overall assistance that the patient received inside the hospital ward? Excellent, good, fair, poor. To perform the multivariate logistic regression analysis, we recoded the caregivers' responses as positive evaluation (excellent or good assistance) or negative evaluation (fair or poor assistance).

<sup>b</sup>ORs (95% CI) were estimated by multivariate logistic regression with the following patient and caregiver covariates included in the model: patient—age at death, gender, marital status, place of residence, primary tumor, months since diagnosis, preferred place of death, period of non-self-sufficiency for everyday tasks, prevalence of pain, prevalence of fatigue, number of patient's cohabitants; caregiver—relationship, age, gender, education, information provided to patients and caregivers regarding treatments, information provided to caregivers in appropriate way, information provided to caregivers about the imminence of the patient's death. Only covariates with a P-value less than 0.10 are reported.



suffering. Moreover, basic information about treatment and care was not given to over two-thirds of patients. Often, the information supplied to caregivers was inadequate. About one-fourth had not received enough information on patient care, and one-third was not informed about the patient's imminent death. After the patient's death, most of the caregivers were not given the opportunity to discuss their feelings with a health care professional.

The high prevalence of very distressing symptoms and the poor outcome of treatments administered to dying cancer patients in hospitals show that the primary goal of death without physical suffering is far from being achieved in Italian hospitals. These results contrast with strong evidence indicating that physical suffering can be effectively relieved through appropriate treatment,<sup>23</sup> and severe, refractory symptoms alleviated through appropriate palliative sedation.<sup>24</sup> The case of very distressing constipation, untreated or poorly treated in most patients, was emblematic of the scarce importance given to the care of dying patients in Italian hospitals.

These results are consistent with those from other studies carried out in many Western countries.<sup>5–12,25</sup> Whenever the care of dying patients in hospital is investigated, the results show a high prevalence of physical and psychological suffering; poor communication between the patient, caregiver, and medical staff; and an underestimation of the caregiver's emotional needs before and after the patient's death.

The improvement of EOL care is being increasingly recognized as an important aspect of health care delivery.<sup>26</sup> In Europe, most cancer patients die in hospital,<sup>2</sup> and recent analyses of future projections<sup>27</sup> suggest that these figures will not significantly decline in future decades. As a consequence, the improvement of the quality of EOL care in hospitals is central to all health care services. The quality of EOL care in hospital depends, for the most part, on the ability of the staff to recognize the imminence of death, to adjust care objectives, and to suspend the dying patient's curative interventions.<sup>28</sup> This can be difficult in hospital, where the culture is focused on cure and where inappropriate procedures, investigations, and therapies are often pursued at the expense of the patient's comfort.<sup>12</sup>

Furthermore, it should be underlined that effective EOL care cannot be implemented without appropriate communication between professionals, patients, and, when appropriate, families or caregivers.<sup>6,11</sup> This is an unavoidable prerequisite for a shared decision-making approach, which effectively allows patients and caregivers to make choices regarding the most appropriate health care and to control key aspects of their lives.<sup>29–31</sup> The results of this survey clearly show that communication with patients and families is often poor; only a minority of hospitalized dying cancer patients received information from physicians about diagnosis, and a negligible proportion received information about the poor prognosis of their disease. As a consequence, information about treatment and care had generally been discussed with the caregivers but not with the patients.

A recent review exploring cancer patients' preferences for information shows an increasing need for greater involvement in the decision-making process and more detailed information about the illness, including prognosis.<sup>32</sup> The reluctance to give bad news to cancer patients probably reflects a persistent paternalistic approach of Italian physicians, particularly outside of specialized cancer centers.<sup>30,33</sup> Moreover, despite the evidence,<sup>11,30,34</sup> physicians still believe that the disclosure of poor prognosis is associated with an increase in patient anxiety and with the loss of a "positive attitude." A recent study by Wright et al.<sup>35</sup> shows that honest, realistic dialogue between physicians and dying patients is not associated with a significant increase in emotional distress. The patients who have the opportunity to discuss EOL care with physicians receive less aggressive medical treatment and are more likely to benefit from hospice services; furthermore, their caregivers experience less regret and show improvements in physical functioning, mental health, and quality of life during the bereavement period.<sup>35</sup>

Regarding the caregiver's emotional needs and feelings after the patient's death, our study shows that, in most of the cases, they are not considered as a part of comprehensive palliative care in a hospital setting. After the patient's death, family members can be helped to cope with their loss by a professional care team, which, through ongoing assessment of specific needs, provides appropriate

counseling and emotional support throughout the bereavement process.<sup>25</sup>

Not surprisingly, about one-third of the Italian caregivers were dissatisfied with hospital services, care provided by medical and nursing staff, and overall care received in hospital. The probability of receiving excellent or good overall care was higher for patients who died in the north of Italy and was associated with a positive opinion of hospital services. It is worth noting that a major determinant of caregiver satisfaction was the quality of information provided by health care professionals to the patient and the caregiver.

As reported by previous articles using the ISDOC survey data, differences between the north and south of Italy were observed with regard to the place of death of cancer patients,<sup>3</sup> the disclosure of diagnosis and prognosis among cancer deceased,<sup>30</sup> the socioeconomic impact on the family during the last three months of the patient's life,<sup>36</sup> and the availability and provision of palliative care programs.<sup>22</sup> In the south of the country, the number of cancer patients dying in hospital is very low, as is the likelihood of cancer patients being informed about diagnosis and prognosis. Furthermore, the distribution of services and programs of palliative care is poor and, consequently, the socioeconomic impact on families who have to look after a cancer patient at the terminal stage of the disease is particularly heavy.

These differences between geographical areas, confirmed by the greater likelihood of satisfaction expressed by caregivers of patients who died in hospitals in northern Italy, have historical roots and could relate to several factors, such as the cultural and social diversities that characterize the geographical areas of the country and the federal administration of the Italian Health Service, which often defines priorities and allocates investments extremely unevenly among Italian regions.<sup>22</sup>

Apart from differences between geographical areas, one of the factors that mainly affects the satisfaction expressed by caregivers appears to be the lack of appropriate and open communication between health professionals, patients, and where appropriate, families. Italian physicians are rarely trained to develop personal skills in communicating and discussing the nature and prognosis of disease and frequently avoid open communication unless specifically requested.<sup>33</sup>

These figures are difficult to interpret, because the concept of "satisfaction with health care" is difficult to define and measure, and most surveys report high degrees of satisfaction.<sup>37,38</sup> Moreover, a systematic review<sup>15</sup> suggests that measuring satisfaction with EOL care may be particularly challenging because the latter differs from medical treatment by units and components of care, dimensions of quality of care, and outcomes.

Williams et al.<sup>39</sup> suggest a possible explanation for the reported high levels of satisfaction: According to their study, a negative experience from a service is reported as a negative evaluation when the concepts of duty (the right to be satisfied) and culpability (the service is responsible for dissatisfaction) are taken into account. It is reasonable to hypothesize that caregivers' expectations for high-quality EOL care in hospital are limited and, as a consequence, their assessment of services through an assessment of their satisfaction is particularly optimistic. This might explain why a high prevalence of pain and other poorly treated symptoms were not associated with dissatisfaction with overall hospital care.

Furthermore, satisfaction surveys on the care of the dying vary from others carried out in the medical care field because most are retrospective<sup>17,37</sup> and have used informal caregivers alone as a source of information. Some evidence of the influence of caregivers' variables on evaluation of services is reported by Fakhoury et al., who found that, although the informal caregivers' high level of satisfaction is mainly determined by service characteristics, it is also influenced by patient and informal caregiver characteristics.<sup>16</sup> The high level of satisfaction expressed by Italian caregivers does not necessarily mean that they have low expectations or that their experience of EOL care was positive; it could simply be linked to the common belief: "... the doctors and nurses did their best ...."

The validity and generalizability of these results must be interpreted taking into account the strengths and weaknesses of the study design.<sup>19</sup> Postbereavement surveys overcome problems related to the practical difficulties of obtaining representative samples of terminal cancer patients.<sup>40</sup> Conversely, this study design is affected by the use of the bereaved caregiver as a source of information. We have to take

into account that the caregivers are not only observers but also participants and recipients and that they evaluate the process of care from their own point of view.<sup>41</sup> A review of studies that compared patients' and proxies' views<sup>42</sup> suggests that proxies can more reliably report on the quality of services and on practical and observable aspects of the patient's experience. For more subjective aspects, such as pain, anxiety, and depression, the concurrence is poorer. Despite this, the caregiver is the only person who can give information about some key aspects concerning EOL care, such as the circumstances of the patient's death, information provided by health care professionals, and the support received after the patient's death.

### Conclusions

The results of this survey show a poor quality of EOL care provision in Italian hospitals, with almost one-third of the caregivers expressing a clear dissatisfaction with the quality of EOL care. In light of this situation, a national policy should be aimed at:

- Training and supporting medical and nursing staff working in hospitals in EOL care;
- Monitoring and assessing the quality of EOL care provided to dying patients in hospital;
- Developing and implementing effective programs to improve the quality of EOL care in hospitals, such as specialized in-hospital palliative care teams.<sup>43–45</sup>

Finally, further research is needed to develop multidimensional models of satisfaction with EOL care that can evaluate care delivery by taking into account the specificity of the palliative care field.

### Acknowledgment

The authors would like to thank Jacqueline Luzardo for data entry.

### References

1. Pantilat SZ, Billings JA. Prevalence and structure of palliative care services in California hospitals. *Arch Intern Med* 2003;163:1084–1088.
2. Davies E, Higginson IJ. *Palliative care. The solid facts*. Geneva, Switzerland: World Health Organization, 2004.
3. Beccaro M, Costantini M, Giorgi Rossi P, et al. Actual and preferred place of death of cancer patients. Results from the Italian Survey of the Dying of Cancer (ISDOC). *J Epidemiol Community Health* 2006;60:412–416.
4. Van den Block L, Deschepper R, Drieskens K, et al. Hospitalisations at the end of life: using a sentinel surveillance network to study hospital use and associated patient, disease and healthcare factors. *BMC Health Serv Res* 2007;7:69.
5. Middlewood S, Gardner G, Gardner A. Dying in hospital: medical failure or natural outcome? *J Pain Symptom Manage* 2001;22(6):1035–1041.
6. Edmonds P, Rogers A. "If only someone had told me ...." A review of the care of patients dying in hospital. *Clin Med* 2003;3(2):149–152.
7. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291:88–93.
8. Sean STA, Low JA, Chan YH. Symptoms and care of dying elderly patients in an acute hospital. *Singapore Med J* 2005;46(5):210–214.
9. Toscani F, Di Giulio P, Brunelli C, Miccinesi G, Laquintana D. How people die in hospital general wards: a descriptive study. *J Pain Symptom Manage* 2005;30(1):33–40.
10. Becker G, Sarhatlic R, Olschewski M, et al. End-of-life care in hospital: current practice and potentials for improvement. *J Pain Symptom Manage* 2007;33(6):711–719.
11. Hancock K, Clayton JM, Parker SM, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med* 2007;21(6):507–517.
12. Sato K, Miyashita M, Morita T, et al. Quality of end-of-life treatment for cancer patients in general wards and the palliative care unit at a regional cancer center in Japan: a retrospective chart review. *Support Care Cancer* 2008;16(2):113–122. Epub October 5, 2007.
13. Pincombe J, Brown M, McCutcheon H. No time for dying: a study of the care of dying patients in two acute care Australian hospitals. *J Palliat Care* 2003;19:77–86.
14. Heyland DK, Groll D, Cocker G, et al. End-of-life care in acute care hospitals in Cabala: a quality finish? *J Palliat Care* 2005;21(3):142–150.
15. Dy SM, Shugarman LR, Lorenz KA, Mularski RA, Lynn J. A systematic review of satisfaction with care at end of life. *J Am Geriatr Soc* 2008;56:124–129.
16. Fakhoury W, McCarthy M, Addington-Hall J. Determinants of informal caregivers' satisfaction with services for dying cancer patients. *Soc Sci Med* 1996;42(5):721–731.

17. Rogers A, Karlsen S. "All the services were excellent. It is when the human element comes in that things go wrong:" dissatisfaction with hospital care in the last year of life. *J Adv Nurs* 2000;31(4):768–774.
18. Addington-Hall J, Walker L, Jones C, Karlsen S, McCarthy M. A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death. *J Epidemiol Community Health* 1998;52:802–807.
19. Costantini M, Beccaro M, Merlo F. The last three months of life of Italian cancer patients. Methods, sample characteristics and response rate of the Italian Survey of the Dying of Cancer (ISDOC). *Palliat Med* 2005;19:628–638.
20. Addington-Hall JM, McCarthy M. The Regional Study of Care for the Dying: methods and sample characteristics. *Palliat Med* 1995;9:27–35.
21. Fusco F. Evaluation of services provided to AIDS patients with advanced stage of disease: a pilot test on the Italian version of VOICES Questionnaire. Thesis of Specialty in Infectious Diseases. Genoa: University of Genoa, 1999–2000.
22. Beccaro M, Costantini M, Merlo DF. Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian Survey of the Dying of Cancer (ISDOC). *BMC Public Health* 2007;7:66.doi:10.1186/1471-2458-7-66.
23. Currow DC, Ward AM, Plummer JL, Bruera E, Abernethy AP. Comfort in the last 2 weeks of life: relationship to accessing palliative care services. *Support Care Cancer* 2008;16(11):1255–1263. Epub March 12, 2008.
24. Sykes N, Thorns A. The use of opioids and sedatives at the end of life. *Lancet Oncol* 2003;4(5):312–318.
25. Eriksson E, Arve S, Lauri S. Informational and emotional support received by relatives before and after the cancer patient's death. *Eur J Oncol Nurs* 2006;10:48–58.
26. Department of Health. End of life care strategy. Promoting high quality care for all adults at the end of life. London, UK: Department of Health, 2008.
27. Gomes B, Higginson IJ. Where people die (1974–2030): past trends, future projections and implications for care. *Palliat Med* 2008;22:33–41.
28. Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life. *Br Med J* 2003;326:30–34.
29. Coulter A. The autonomous patient. Ending paternalism in medical care, 3rd ed. London, UK: Nuffield Trust, 2002.
30. Costantini M, Morasso G, Montella M, et al. Diagnosis and prognosis disclosure among cancer patients. Results from an Italian mortality follow-back survey. *Ann Oncol* 2006;17:853–859.
31. Jiang Y, Liu C, Li JY, et al. Different attitudes of Chinese patients and their families toward truth telling of different stages of cancer. *Psychooncology* 2007;16(10):928–936.
32. Back AL, Arnold RM, Baile WF, Tulskey JA, Fryer-Edwards K. Approaching difficult communication tasks in oncology. *CA Cancer J Clin* 2005;55(3):164–177.
33. Bracci R, Zanon E, Cellerino R, et al. Information to cancer patients: a questionnaire survey in three different geographical areas in Italy. *Support Care Cancer* 2008;16(8):869–877.
34. Fallowfield LJ, Hall A, Maguire GP, Baum M. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *Brit Med J* 1990;301:575–578.
35. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300(14):1665–1673.
36. Giorgi Rossi P, Beccaro M, Miccinesi G, et al. Dying of cancer in Italy: impact on family and caregiver. The ISDOC survey. *J Epidemiol Community Health* 2007;60:546–553.
37. Fakhoury W. Satisfaction with palliative care: what should we be aware of? *Int J Nurs Stud* 1998;35:171–176.
38. Aspinall F, Addington-Hall J, Hughes R, Higginson IJ. Using satisfaction to measure the quality of palliative care: a review of the literature. *J Adv Nurs* 2003;42(4):324–339.
39. Williams B, Coyle J, Healy D. The meaning of patient satisfaction: an explanation of high reported levels. *Soc Sci Med* 1998;47(9):1351–1359.
40. Earle CC, Ayanian JZ. Looking back from death: the value of retrospective studies of end-of-life care. *J Clin Oncol* 2006;17(5):785–793.
41. Kristjanson LJ. Quality of terminal care: salient indicators identified by families. *J Palliat Care* 1989;5(1):21–30.
42. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? *Soc Sci Med* 2003;56:95–109.
43. Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage* 2003;25(2):150–168.
44. Hanson LC, Usher B, Spragens L, Bernard S. Clinical and economic impact of palliative care consultation. *J Pain Symptom Manage* 2008;35(4):340–346. Epub February 8, 2008.
45. Morrison RS, Penrod JD, Cassel JB, et al. Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med* 2008;168(16):1783–1790.

## *Appendix*

### *Members of the Italian Survey of the Dying of Cancer Study Group*

Massimo Costantini, Monica Beccaro, and Silvia Di Leo (Regional Palliative Care Network, National Cancer Research Institute, Genoa); Maria Pia Sormani (Unit of Biostatistics, Health Sciences Department, University of Genoa); Paolo Bruzzi (Unit of Clinical Epidemiology, National Cancer Research Institute, Genoa); Domenico Franco Merlo (Epidemiology and Biostatistics and Clinical Trials and Bioethics, National Cancer Research Institute, Genoa); Gabriella Morasso (Psychology Service, National Cancer Research Institute, Genoa); Paolo Giorgi Rossi, Piero Borgia (Agency for Public Health, Lazio Region, Rome); Maurizio Montella, Maria Grimaldi (Department of Epidemiology, National Cancer Institute, G. Pascale Foundation, Naples); Eugenio Paci, Nicoletta Susini, Riccardo Cecioni, Guido Miccinesi (Clinical Epidemiology, Centre for the Study and Prevention of Cancer, Florence); and Renato Pisanti (Labos Foundation, Rome).