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Assessing quality of end-of-life hospital care in a southern European regional health service

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Objectives: During the final period of life, patients with cancer in the Basque Country are given treatment in different types of hospital care. This study compared the quality of care according to the type of care in one of the autonomous communities in Spain.
Methods: A retrospective study was carried out of cancer patients who died in conventional hospital services, home hospitalization services, and palliative care units. In addition to hospital stay and readmission number, variables based on the recommendations of Spanish Society for Palliative Care were studied.
Results: End-of-life was diagnosed in 57 percent of a sample of 486 patients, 3 days before death (median). The use of symptom control scales was only documented in the clinical records of eight patients. Sociofamily evaluation was not found. Patients in conventional hospital services were less frequently diagnosed with end-of-life and agony and were significantly different from the rest in the reasons for admission, symptoms assessed, drugs used, administration routes, and dosage forms. Pain was evaluated in 50 percent of the patients and was better controlled in palliative care units. Patients not diagnosed with agony (52 percent) were more frequently not given specific treatment.
Conclusions: End-of-life in cancer patients was diagnosed too late. The quality of care in palliative care units and by home hospitalization service was better than that in conventional hospitalization. Nevertheless, there were areas for improvement in the three modalities of care.

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Interest in palliative care has extended worldwide. In a monograph about National Cancer Control Programs (30) published by the World Health Organization, pain relief and palliative care were added to the classic approaches to cancer control based on primary prevention, early detection, diagnosis, and treatment. This new approach emphasizes both the importance of life, death being treated as a natural occurrence (20), and the need of establishing a process that does not speed up or postpone its arrival. A model of care is being proposed in which therapies that try to modify the disease gradually lose intensity as the disease develops. The provision of palliative care is increased as the person nears the end-of-life, including support for the family throughout this period, and continues after the death of the patient with bereavement counseling (30).

During recent years, sensitivity with regard to the different kinds of situations that accompany end-of-life has increased in Spain. More precisely, in the Basque Country, several palliative care units (PCU) focused on the specific care of these patients and home hospitalization services (HHS) have been put into operation. These units offer an alternative to conventional hospital care models. Nevertheless, the idea that palliative care should be limited to the care process in the last days of a patient's life prevails.

Previous studies have shown that hospital-based palliative care units attained better symptom control (5;21;23;24), a greater reduction in the anxiety of patients (28), and a greater likelihood of them contacting social services (17) than the clinical services of acute care hospitals. The importance of hospital professionals attending to patients at home has also been analyzed (7). Lastly, other studies focused on hospital use (13) or on the compliance with quality standards (2) in patients with cancer at end-of-life admitted to teaching hospitals. However, there is no scientific evidence concerning the quality of palliative care in Spain. In this study, we compared the quality of the care provided to patients at end-of-life in conventional hospital units with that provided by hospital units specifically focused on these types of patients and home hospitalization services.

PATIENTS AND METHODS

A descriptive survey was carried out retrospectively to evaluate the quality of care received during the hospital stay when death occurred. Cancer patients at the end-of-life who received conventional hospital care were compared with those who were attended in units more focused on the care of these patients. Additionally, a retrospective monitoring of patients during the last 6 months of life was carried out to identify the date at which end-of-life had been diagnosed and to estimate the number of admissions and days spent in care. The study period covered the first 6 months of the year 1997. The study was carried out in twelve acute care hospitals, five home hospitalization services, and two palliative care units of Osakidetza/Basque Health Service. Conventional hospitalization included all the different services provided at acute care hospitals that dealt with oncology patients. Palliative care units were specific units located in long and medium-term hospitals (hospital for patients with chronic diseases). Home hospitalization services were teams of hospital professionals (doctors and nurses) who provide care at home.

The study subjects were selected from the Hospital Discharge Register. A stratified random sample was selected from all cancer patients who died in the hospital during the study period, according to type of care and hospital. Sample size (11) was calculated to estimate a proportion of 0.50, with a sampling error of 0.05, and a confidence level of 95 percent.

The medical records of study subjects were reviewed and then transcribed in an *ad hoc* questionnaire, with special attention to selected variables according to recommendations established by the Spanish Society for Palliative Care (16), and by the Edmonton General Hospital (18). Data of end-of-life diagnosis, drug administration routes (oral, subcutaneous, and dural, which are recommended versus intravenous), feeding methods (oral, which is recommended versus feeding tube, parenteral, and total diet), the use of symptom assessment scales, psychological and sociofamily appraisal, typification of pain, dosage forms for opioids ("at regular intervals" which is recommended versus "as required"), combined use of opioids and laxatives, and agony diagnosis. In addition, hospital stay, number of readmissions, symptoms assessed, drugs used, and sedation were recorded.

In the absence of a specific diagnosis of "end-of-life", this diagnosis was deduced when the medical record suggested the absence of curative treatment by notes such as "do not do anything," "terminal situation," or "only treat if in pain."

Data analysis included the calculation for absolute and relative frequencies for categorical variables, and the mean and standard deviation (SD) or the median and interquartile range (IR) for quantitative variables. The hypothesis testing for proportions was the chi-squared test. For the median comparison, the Mann-Whitney test was used. All the calculations were made with the SAS statistics package.

RESULTS

The study included 486 patients with a median age of 67 years (IR:18), 67 percent of which were men. The place of death, in order of frequency, was conventional hospitalization

Table 1. Age, Sex, Tumor Locations, Symptoms Assessed, Drugs Used, and Sedation during Hospital Stay when Death Occurred (Basque Country, Spain)

			Conventional hospitalization $N = 307$	Home hospitalization services $N = 64$	Palliative care units $N = 115$
Age		Median (IR)	67 (17)	66 (21)	67 (17)
Sex	Men	% (*n*)	65[a] (199)	59 (38)	77[a] (88)
	Women		35 (108)	41 (26)	23 (27)
Location	Lung		16 (48)	16 (10)	33[b] (38)
	Colon–rectum		18 (54)	13 (8)	5[b] (6)
	Genitourinary system		12 (36)	9 (6)	12 (14)
	Stomach		10 (30)	9 (6)	5[b] (6)
Symptoms assessed	Pain		55 (170)	55 (35)	35[b] (40)
	Dyspnea		31 (95)	27 (34)	25 (29)
	Vomiting		26 (80)	30 (19)	10[b] (12)
Analgesic therapy			77 (236)	80 (51)	88[b] (101)
Drugs used	Opiates "at regular intervals"		52[b] (161)	67 (43)	74 (85)
	Corticoids		31 (95)	36 (23)	52[b] (60)
	Antibiotics		33 (102)	13[b] (8)	24 (28)
	Laxatives		17[b] (51)	38 (24)	43 (50)
Sedation			22[b] (68)	14 (9)	9 (10)

[a] Statistically significant difference ($p < .05$) between men and women.
[b] Statistically significant difference ($p < .05$) between care settings.

(63 percent), palliative care units (24 percent), and home hospitalization services (13 percent). The proportion of men was greater in conventional hospitalization and palliative care units, but there were no age differences between patients in the three care settings.

Neoplasms of the lung, colon–rectum, genitourinary system, and stomach, represented more than 50 percent of total cancer sites. Patients in PCUs were more frequently affected by lung cancer. Nevertheless, the colon–rectum and stomach neoplasms were significantly less frequent.

The most frequently assessed symptoms were pain, dyspnea, and vomiting. Both pain and vomiting were much less frequent in palliative care units, and the administration of analgesics was substantially higher. The most commonly administered drugs were opiates at regular intervals, laxatives, antibiotics, and corticoids.

Sedation was more common in conventional hospitalization. The median duration of the sedation was 1 day (IR:2), there being no differences between types of care (Table 1).

Differences were observed in the reasons for admission. In conventional hospitalization, patients were admitted for a variety of causes, such as progressive deterioration, pain, or dyspnea, whereas all patients in home hospitalization services and 74 percent of those in the palliative care units were admitted for symptom control (Figure 1).

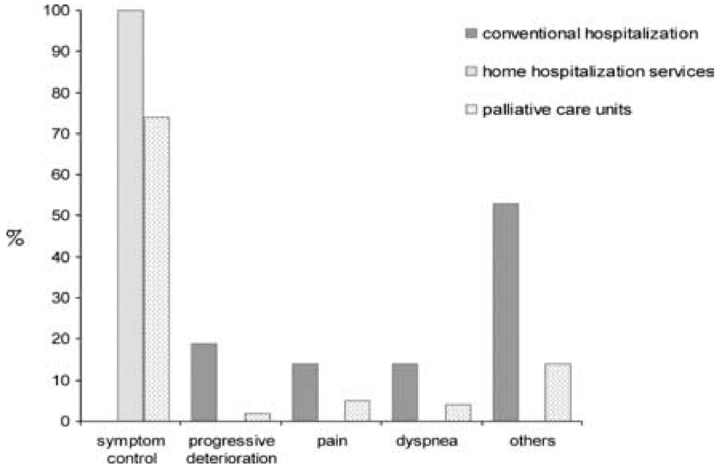

Figure 1. Reasons for admission to hospital stay when death occurred, distributed according to hospital care model (Basque Country, Spain).

Table 2. Differences in the Compliance of the Spanish Society of Palliative Care Recommendations between the Three Hospital Care Settings (Basque Country, Spain)

		Conventional hospitalization $N = 307$	Home hospitalization services $N = 64$	Palliative care units $N = 115$
		% (n)		
End-of-life diagnosis		39[a] (119)	96 (50)	97 (107)
Agony diagnosis		44 (135)	56 (36)	71[Ψ] (82)
Administration routes	Oral	10[a] (32)	66 (41)	56 (65)
	Intravenous	89[a] (274)	3 (2)	30 (34)
	Subcutaneous	10 (32)	32 (20)	39 (45)
	Dural	0.3 (1)	1.6 (1)	1.7 (2)
Opioids and laxatives		12[a] (38)	27 (17)	38 (44)
Type of feeding	Oral	73 (223)	75 (48)	80 (92)
	Feeding tube	9 (27)	3 (2)	6 (7)
	Parenteral	3 (9)	2 (1)	1 (1)
	Total diet	12 (36)	3 (2)	5 (6)

[a] Statistically significant difference ($p < .005$) between care settings.

The end-of-life diagnosis rate was significantly higher in HHS and PCU than conventional hospitalization. The median time between the end-of-life diagnosis date and death was 3 days (IR:10).

Differences in drug administration routes clearly showed that, in conventional hospitalization, intravenous drug administration was predominant, the use of oral and subcutaneous routes was scarce, and the combined administering of opioids and laxatives was significantly smaller. In the three different types of care settings, no differences were found in the type of feeding. The agony process was diagnosed in half of the patients, and frequency of agony diagnosis in PCUs was significantly higher than in HHS and conventional hospitalization (Table 2).

Pain was registered in 50 percent of patients. Home hospitalization services and palliative care units preferably prescribed opiates "at regular intervals." In conventional hospitalization, however, the prescription of opioids "as required" and the use of nonopioids analgesics was more frequent (Table 3).

The use of pain control records and their typification was only documented in the medical records of eight patients, and the psychological and sociofamily appraisal was not found.

At the moment of agony, the administering of opiates "at regular intervals," antianxiety agents, and neuroleptics was significantly higher in patients with an agony diagnosis. On the other hand, no specific treatment was given to those patients who had not been diagnosed with agony (Table 4). During this stage, the only change observed in the pattern of treatment was the general increase in the administering of opiates "at regular intervals."

A subanalysis was made, stratified according to sex, to determine whether there were significant differences between men and women in the quality of care. It was found that pain was significantly higher in women, and the number of patients treated with opiates at regular intervals was also higher in the feminine sex. No differences were found in the remaining care-related variables.

Table 3. Analgesic Drugs Used in Patients Whose Pain Has Been Assessed (Basque Country, Spain)

Treatment	Conventional hospitalization $n = 170$	Home hospitalization services $n = 35$	Palliative care units $n = 40$
	% (n)		
Opiates "at regular intervals"	64[a] (109)	74 (26)	85 (35)
Opiates "as required"	19[a] (32)	—	3 (1)
Non-opioid analgesics "at regular intervals"	34 (57)	20 (7)	18 (7)
Non-opioid analgesic "as required"	11 (19)	6 (2)	5 (2)

[a] Statistically significant difference ($p < .05$) between care settings.

Table 4. Treatment Prescribed in Accordance with Performance of Agony Diagnosis (Basque Country, Spain)

	Agony diagnosis	
	Yes $N = 252$	No $N = 232$
Agony treatment	% (n)	
Opiates "at regular intervals"	54[a] (137)	17 (39)
Antianxiety	22[a] (56)	8 (18)
Neuroleptics	19[a] (49)	4 (9)
Unspecific	21[a] (52)	59[a] (136)

[a] Statistically significant difference ($p < .05$).

During the last 6 months of life, the median of admissions in conventional hospitalization was two (IR:1) and the median hospital stay was 24 days. The values of IR were from 14 to 43 days, which means that 25 percent of patients remained in the hospital more than 43 days. In home hospitalization services, the behavior was very similar. The median of admissions was two (IR:1), and the median of stay was 27 days. However, in palliative care units, 97 percent of patients had one admission with a median stay of 8 days.

DISCUSSION

This study demonstrates that the diagnosis of the end-of-life stage was performed too late in the course of the original disease (cancer), as it was left to the last days of life, and depending on the type of care, the quality of health care was different. For the first time in Spain, this survey set out the differences between hospital care models that attend to patients at the end-of-life.

One of the basic findings of this survey was the short amount of time between the diagnosis of end-of-life and death. It is practically impossible to plan a care program for patients and their families 3 days before death. In other geographical areas, there is also the certainty that the referral of patients with cancer to palliative care occurs too late (3). One of the main reasons for this is the difficulty of establishing a boundary between the curative and palliative approach. Fortunately, for some time now, work has been done on models that take into consideration the biological situation and also the respect of the patient's autonomy (22).

The most frequent reasons for admission to the hospital during the last hospital stay, that is, to control pain and other symptoms and progressive deterioration, are in agreement with those found in other studies (14;24). The use of different terms was observed according to the type of care, which might reflect the different approach to end-of-life in conventional hospitalization and the other care models. Whereas the term "progressive deterioration" seems to suggest a passive attitude, the term "symptom control" conveys a more active attitude toward obtaining the highest level of comfort possible for the patient.

The differences found in prescribed treatments between conventional hospitalization and the palliative care units were described in a comparative study made in United Kingdom, where it was seen that quality standards were met less frequently in general hospitals (24). As in the case of other studies carried out in different geographical areas (2), pain was the most common symptom and appeared in half of the patients. A review of the literature provides heterogeneous information about the management of pain. Thus the studies carried out in acute care hospitals (6;15) have provided a pain prevalence range of 31 to 80 percent. It should be pointed out that, as shown in the scientific evidence, specialist hospital-based palliative care services control pain the best (21). The causes most commonly described as being responsible for deficient pain control are linked to process components and not therefore to structural resources (5), specifically, the insufficient use of measurement scales and strong opioids, and suboptimal patients pain knowledge.

The incidence of sedation estimated in this survey is not high (26;27) (reported frequency, 5 to 52 percent) (4), as even the incidence corresponding to conventional hospitalization comes within the range observed (22) in Spanish palliative care units. The low frequency of agony diagnosis, when there are symptoms and signs that characterize (25) this situation clearly is also a relevant finding, because it may involve the decision "not to do anything." The generalized increase in the use of opioids, on reaching the moment of agony, in all types of care, has been pointed out previously (12).

During the last 6 months of life, the patients stayed in acute care settings for longer periods of time than in other settings. The most important reason could be that family relies on the physician who treats the oncology process. The mean of days spent in conventional hospitalization (30) was higher than that found in Australian (14) and London (19) hospitals. However, in the Swedish study (1), which was carried out in a county where there were no specialized units, they found that the period of stay was higher than that of the hospitals of Osakidetza/Basque Health Service. The aforementioned argument is based on the hypothesis that home care during the end-of-life, provided by trained personnel, reduces the periods of hospitalization in acute care hospitals (8;10;19).

Although the orientation of this survey was retrospective, that at end-of-life most patients were admitted to control their symptoms, especially pain, was well documented. This finding might indicate that the patients had not been provided with the palliative care the situation required. For this reason, the need to improve the hospital care given to these patients is clear, as is the fact that efforts must be directed, first, toward those centers that provide personal assistance without specific training in palliative care. To provide adequate care, health service professionals must have both the appropriate attitude and aptitude. Therefore, they must acquire knowledge to provide palliative care both at the first level, as well as at the second and third levels (29).

The virtual absence of symptom evaluation scales, psychological and sociofamily assessment, and typification of the pain may be due either to a lack of documentation in medical records or to it not being included in the clinical practice of the center. On the other hand, as the conventional hospitalization sample was the largest, individual estimations were more accurate than the others. The opposite occurred with home hospitalization services, and it is possible that, on some occasions, the existing differences have not been detected.

Finally, it is important to emphasize the need to continue research work into palliative care to collect more evidence on the effectiveness of the services and care techniques. That it is more difficult to carry out randomized clinical trials in this field does not mean that the study should not be carried out with descriptive and observational design (9). In the same way, part of this research should be oriented toward the patients with chronic diseases other than cancer.

Policy Implications

An improvement in health care quality would be to ensure that the same intensity of care at the different settings is applied when a program for patients at the end-of-life is implemented. Also, the principles of palliative care should be applied as early as possible during a chronic and fatal illness. Medical education programs, coordination of resources, and research that considers the opinion and beliefs of patients and families are necessary.

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