

How patients die in an Internal Medicine ward: a retrospective study

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Abstract

Terminal patients are a daily presence in our medical wards, but there is no universal, standard protocol for their palliative care. Terminal patients are daily present in our medical wards, and there is no universal standard protocol for palliative care. The aim of this work is to be an observational study, in order to see how we treat and how we care for our terminal patients, including cancer patients, as well as other chronic diseases as dementia, heart failure, HIV/AIDS and chronic obstructive pulmonary disease. A retrospective analysis of 286 clinical files of deceased patients, in a 16 month period, in a Lisbon hospital was made. The epidemiologic characterization was, as expected, an old and dependent population, with a major presence of cardiovascular diseases

followed by respiratory diseases. Regarding the population, 73% of deaths were expected, but just 44% were considered to be in palliative care. Pain was evaluated predominantly in cancer patients, being treated in 77% of cases. The decision of palliative care was discussed with the family in 26% of patients, but it was not discussed with the patient him/herself. Education in this area is necessary in order to make a systematic intervention with terminal patients. A definition of patients' expectations and systematic pain research in all terminal patients is needed to improve quality of end-of-life care.

Key words: palliative care, chronic disease, pain.

INTRODUCTION

Terminal stages of chronic, progressive and restrictive diseases are associated with the presence of multiple symptoms, and are a cause of suffering for patients and their families. Some of these symptoms, like pain, dyspnea and extreme fatigue, and emotional states, such as anxiety, depression, and feelings of uselessness, are common in our wards.^{1,2} Of these symptoms, pain is one of the most frequent, and the most feared,³⁻⁶ but it is underdiagnosed and undertreated, even in patients assumed to be in end of life care.

Until recently, it was accepted that patients who died of non-neoplastic disease did not have high levels of pain. However, various studies⁷⁻¹⁷ demonstrate that terminal patients with heart failure, COPD, renal failure, HIV/AIDS and neurodegenerative disease may have pain levels that are similar to those of cancer patients. At the end of their lives, the majority of patients prefer to remain at home, but unfortunately, many end up dying in the hospital environment, due to the family's inability to give adequate care, or due to some complication that they do not feel qualified

to deal with. Many patients with non-neoplastic advanced chronic disease belong to the habitual population of the Internal Medicine wards. However, few studies have been carried out on the specific needs for palliative care in this population.^{1,4,5,14,29}

It was the lack of studies in Portugal that would enable a better evaluation of the needs of these patients that prompted us to carry out this work.

OBJECTIVE OF THE STUDY

- Epidemiological characterization of patients who died in a 16-month period, at the Internal Medicine Service 2 of Sao Jose Hospital – Lisbon Hospital Centre (CHL).
- Classification of the patients into: patients whose death was expected/unexpected; patients who received/did not receive palliative care.
- Analysis of patients who received palliative care.
- Analysis of medical attitudes towards patients in the last few days of life.

MATERIAL AND METHODS

A retrospective study of patients who died in an Internal Medicine ward between the 1st January 2005 and the 30th April 2006.

The data were collected based on clinical process.

Variables studied: demographic data, length of

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hospital stay; previous hospitalizations (in the last 12 months); patient's origin; degree of independence on the date of hospitalization; reason for hospitalization; main diagnosis; comorbidities; symptoms in the last 20 years of life; whether or not the death was expected; whether the assistant doctor considered the need for palliative care; the cause of death; and whether resuscitation manoeuvres were carried out.

The definitions were standardized based on the literature, or on the consensus of the team that carried out the study.

- Patients receiving palliative care were defined as all those, whose clinical diary explicitly stated this information. For these patients, the following supplementary data were gathered: a) whether the family had been directly involved in the decision to provide palliative care; b) whether after this decision, complementary diagnostic exams were carried out; c) use of antibiotics; opioids; and maintenance of central venous catheterization in the last 8 days of life.

- In all the patients, it was determined whether death was the most plausible outcome for the situation, according to the express clinical notes, and which would have given these patients the advantage of receiving palliative care. This selection was based on the definition of patients requiring palliative care, of the National Palliative Care Program,¹⁸ considering all the patients with chronic diseases, who did not respond to curative treatment, and with a recognized prognosis of limited life.

Due to the difficulty in applying a functional scale, the patient's *degree of independence* on the date of admission was based on the analysis of the nursing records, classifying them as "independent" if the patient did not require help in his or her daily activities, "partially dependant" if they needed supervision and some help, and "dependant" if they were incapable of performing basic tasks.

RESULTS

In the period of time analyzed, 285 deaths occurred, corresponding to 11.16% of the total number of admissions.

The general characteristics of the study population are summarized in *Table I*.

The average age of the patients was 77.7 years (min- 30; max-98), with 66% being aged between 70 and 89 years, and no differences between the sexes. 98.6% of the patients were Caucasian.

Table I

General characteristics of the population

Variable		n= 285	%
Gender	Female	145	50,9
	Male	140	49,1
Mean age		77,7 years	
Caucasian		281	98,6
Length of hospital stay (median)		7 days	
Length of hospital stay (mean: min-1; max-174)		14,3 days	
Previous hospitalizations (12 months)		105	36,8
Place of origin		228	80,0
Degree of dependence	Independent	66	23,2
	Partially dependant	77	27,0
	Totally dependant	142	49,8

We observed that 80% of the population had come from their own homes, 17% from a social institution, 2% from other hospitals, and 1% from retirement homes. 76.8% of the patients were totally or partially dependant on the day of hospitalization.

There was a record of a previous hospitalization in 30% of the patients, and more than one hospitalization in 7% of the patients.

In terms of the reason for admission, the most frequent was due to general symptoms (32%). In the more advanced age groups, this was followed by respiratory symptoms (26%), while in those under 60 years of age (n = 35), cardiovascular symptoms were prevalent.

In relation to the main diagnosis (*Table II*), diseases of the circulatory system (including heart pathology and AVC) were the most frequent, followed by diseases of the CVA (including dementia) and cancers.

Also significant was HIV/AIDS infection, in 5% of patients, predominantly among Caucasian males, with an average age of 46.3 years (min- 33; max- 78). These patients had had at least one hospitalization in the last year; the main reason for hospitalization, and the principal diagnosis, was infectious pathology.

In relation to comorbidities, the majority of the patients (90.5%) had at least one comorbidity, the most

Table II

Diagnoses by nosological group

Variable		n= 285	%
Diagnosis	D. Infectious	18	6,3
	D. Cardiovascular	92	32,2
	D. CNS	57	20,0
	D. Genito urinary	5	1,7
	D. Respiratory	28	9,8
	D. Gastro intestinal	19	6,7
	D. Neoplastic	63	22,1
	D. Hematological	3	1,0

TABLE III

Causes of Death

Variable		n=285	%
Cause of death	D. Infectious	26	9,1
	D. Cardiovasc.	91	31,9
	D. CNS	3	1,0
	D. Genito urinary	4	1,4
	D. Respiratory	115	40,4
	D. Gastro intestinal	11	3,9
	D. Neoplastic	34	11,9

frequent being arterial hypertension (42%), followed by ischemic cardiopathy (35%), heart failure (28%) and dementia (27%). In the younger age groups, the most frequent comorbidities were infectious – chronic hepatic disease associated with hepatitis C and hepatitis B and ethanolism.

The most frequent cause of death (*Table III*) was respiratory infection. However, a prevalence of neoplastic disease and HIV was seen in the younger age groups. Respiratory infections were the most common cause of death after 60 years of age.

There were two mortality peaks; one earlier, in the 48 hours of after admission (n=77) and the other later, after 48h (n=208).

Of the symptoms analyzed in the 20-day period preceding death (*Table IV*), the most frequent was dyspnea, followed by bronchitis and fever.

TABLE IV

Symptoms in the 20 days preceding death

Symptom	n=285	%
Exhaustion	61	21,4
Delirium	7	2,5
Mental confusion	47	16,5
Psychomotor agitation	62	21,7
Dispnea	217	76,1
Bronchorrhea	152	53,3
Fever	147	51,6
Pain	63	22,1
Vomiting	64	22,5

It should be highlighted that in the patients with diseases of the CNS as a cause of death, the most frequent signal was exhaustion, while in the patients with neoplastic disease, the most frequent symptom was pain.

Pain was described in a significant number of these patients (22%). Of these, 54% were treated with opioids. The patients with neoplasias (n=63) had a higher frequency of pain (55.5%) and of these, 77% were treated with opioids. Of the other groups diagnosed (n=222), pain was recorded in 12.6% and treated with opioids in 25% of cases.

In the majority of the patients (n=207), death was expected (*Table V*), while just 125 were assumed to be patients receiving palliative care. Resuscitation manoeuvres were performed in 21%, and autopsy was performed in 4% of the patients.

In the group of patients receiving palliative care (n=125), the most common main diagnoses were cancer (32.8%; n=41); cardiac disease (35.2%; n=44); and neurological disease (16%; n=20). In 26% of the patients, the decision to receive palliative care was discussed with the family, however, in this series, no case was added in which the decision was also discussed with the patient him/herself; 23% of the patients underwent complementary diagnostic exams (upper endoscopy, computed axial tomography, scintigraphy) after the decision to receive palliative care; 17% had a central venous catheter (CVC) in the eight days preceding death, and 74% were under antibiotics in this same period; 42% were prescribed opioids.

TABLE V

Patients in whom death was expected/Palliative care

Variable	n=285	%
Death expected	207	72,6
Palliative care	125	43,8

None of the patients receiving palliative care were subjected to resuscitation manoeuvres or autopsies.

DISCUSSION AND CONCLUSIONS

This study has some limitations: it is a retrospective analysis, based on clinical processes and dependant on written information, which is often incomplete; the sample used does not reflect the national population, as the clinical and nursing practice is that of a central hospital; the analysis of some of the data found is subjective, due to a lack of uniform criteria in the description of patients, signs and symptoms.

Despite the above, it seeks to be an initial approach to the clinical practice for end of life patients.

The characteristics of the study population are similar to those found in our studies:^{2,4,7,18-21} with a prevalence of elderly, dependant individuals and multiple comorbidities; but also the presence of young patients with HIV/AIDS infection and cancers that present special needs.²²⁻²⁶

In the diagnoses found, there was a prevalence of cardiovascular diseases, diseases of the CNS and cancers, but as a terminal event, the most prevalent was respiratory infections.

Of the 285 patients who died, we emphasize that although in 207 of these, death was expected, only 125 received palliative care.

As in other studies,³ there was a tendency to carry out measures that prolong the patient's life, but without these having any beneficial effect on the quality of life. On the other hand, the expectation that cancer patients have a higher level of pain than the other patients appears to be a factor that prompts more studies on this disease. However, this does not mean that the other patients may not also experience pain, but which is underdiagnosed.^{7-9,14,27} At least half of the patients were prescribed opioids. Various studies have demonstrated the inadequate control of pain in end of life patients, whether in neoplastic or non-neoplastic pathologies,^{1,15} despite the fact that its

control is an essential element for comforting patients and their families.

The hospitals that deal with acute cases have little standardization of the care provided for end of life patients, and sometimes this care is lacking, with difficulty approaching families and in decision-making to ensure the most adequate measures. Over the last few decades, we have seen a decline in the number of extended families, and less availability of family members to care for patients, with this responsibility being transferred to the hospitals and the Health System. These institutions have adapted poorly to the rapid changes in the structure of our society, with evident difficulties communicating and understanding patients and their families.

This study reveals the difficulty of the healthcare team in assuring that patients benefit from palliative care; the number of patients receiving care that is less than would be desired, and there is a need to optimize the palliative measures and attitudes for end of life patients. The emergence of chronic diseases has led to death being a more frequent occurrence, at the end of a prolonged course of the disease. However, the fact of living longer does not necessarily mean a better death. The humanization of the structures of the Health System is essential for ensuring better care.

The care provided at the end of life requires trained professionals, and should be included as one of the performance indicators of the health systems.^{18,28} Chronic patients have different needs. Given the frequency with which we find these patients in our wards, specialized, systematic training of doctors and nurses is justifiable.

Despite the recommendations of various countries and associations, the inclusion of these recommendations in clinical practice will only become possible if they are understood through continual training and a change in mentalities, favoring the patient's well being and quality of life, to the detriment of futile therapies that form part of a culture that negates death. ■

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