

Reality of Palliative Care

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-----ABSTRACT-----

Palliative care aims to improve the life quality of patients and their families facing problems arising from a life-threatening illness. Despite the development of palliative care resources, recommendations are still late and their use is still inadequate. The aim was to investigate the reality of a cancer hospital with regard to transfer and the provision of palliative care. Recommendation for palliative care occurred in 47.3% of patients. The median time between cancer diagnosis and death was 18 months. Sixty-two days passed between the last antineoplastic treatment and the date of death and between the access and the recommendation for palliative care passed 14 days. The median length of stay in palliative care until death was eight days. Patients under 65 had a shorter period between their last treatment and death, and between recommendation and death, compared to those aged 65 and over. Patients, who received palliative care had more cases of death considered peaceful, compared to those who did not. Despite the availability of palliative care, a large percentage of patients still do not benefit from it. Palliative care needs to be introduced more into medical and nursing training.

Keywords: *palliative care; recommendation; life quality.*

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I. Introduction

At the end of the 1960s, in London, the “hospice movement” - pioneered by Cicely Saunders - drew attention to the needs of people at the end of their lives, recognizing the importance of medicine not only in curing disease, but also in accompanying patients suffering from incurable pathologies. Cicely Saunders created St. Christopher's Hospice in London in 1967, an institution recognized as a pioneer in palliative care[1]. The term “palliative care” appeared in 1975 with the creation of the Palliative Care Service at the Royal Victoria Hospital in Montreal by Balfour Mount. Palliative care, as “active and total care provided to patients whose illness does not respond to curative treatment” was defined by the World Health Organization (WHO) in 1990. This description was reformulated in 2002, and palliative care was defined as an “approach that aims to improve the quality of life of patients and their families facing problems arising from a life-threatening illness, through the prevention and relief of suffering, using early identification, appropriate assessment and rigorous treatment of pain and other physical, psychosocial and spiritual problems”[2].

WHO reinforces the relevance of palliative care by considering it a health policy priority. According to this organization, palliative care is based on the following principles:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards death as a normal process; does not seek to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system for the needs of the patient and family during illness and bereavement, using a multidisciplinary approach;
- Improves quality of life and can thus positively influence the course of the disease;
- and is applicable from the beginning of the course of the disease, in conjunction with other so-called curative therapies such as chemotherapy or radiotherapy, doing everything to better understand and manage the distressing clinical complications that can arise during the course of treatment [2].

Tumors are responsible for around 25% of mortality [3]. Palliative care is an ethical duty that reflects the fundamental human right to a dignified death. Therefore, medical training should prepare future clinicians for the moment when technical aspects alone leave them unarmed, for the moment when nothing can be done for the disease, but a lot can still be done for the patient, and even for the moment when they will have to establish life goals with the patient, in the perspective of the possibility of death, despite being diligently trained to cure.

II. Methods and Materials

The clinical files of patients who died while hospitalized during the first half of 2022 were consulted, after formal consent from the hospital's Ethics Committee and a request to the Clinical Archives for the respective list. The aim was to find out under what conditions these individuals died:

1. when they had their last treatment for the disease;
2. whether they had been referred for palliative care, whether they had been admitted to the hospital's palliative care service or another, and how long they had been waiting for this, as well as the number of days they had been in hospital;
3. whether they had remained in the service of origin and whether they had received palliative care there;
4. and whether their death was peaceful or not.

A data collection form was created and fully completed. The data was analysed using simple statistical methods.

III. Results

Of the 572 patients discharged from hospital due to death during this period, 121 were invalidated for different reasons. Thus, 451 patients were included in the study. In demographic terms, the sample included 292 males and 159 females, whose age followed a normal distribution and averaged 64.25 years (± 11.41). In terms of diagnosis (Fig. 1), gastrointestinal tumors were the most common, followed by lung tumors and haematological tumors.

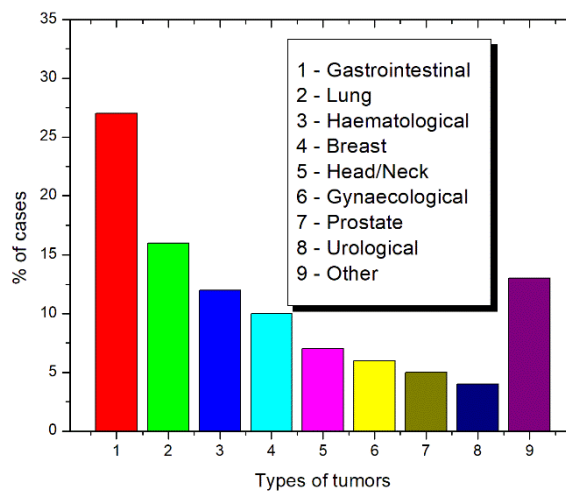


Fig. 1: Diagnosis of tumors.

At the time of death, 69.2% of the patients had metastasized (Fig. 2). We also investigated the existence of comorbidities in the patients involved, which were present in 73.6% of cases.

Patients were admitted for medical oncology (58.9%); 10.7% for surgical oncology, 9% for oncohematology and 0.6% for radiotherapy. Nineteen percent of patients were admitted to the palliative care service from the outset. The reason for admission in 68.4% of the cases was to provide palliative care, including symptom control, supportive treatment and end-of-life care.

Roughly 10% were hospitalized due to progression of the disease with a later decision not to continue with antineoplastic treatment. 6.6% due to complications from treatment. 3.6% due to acute situations apparently unrelated to the cancer pathology. 3.2% to study the pathology. 3% for antineoplastic treatment but with a later decision not to continue. 1.7% due to progression of the disease but without a decision not to continue the treatment directed at the disease. 1.3% due to complications of the treatment with a subsequent decision not to continue the antineoplastic treatment. 0.9% for chemotherapy, 0.8% for surgery and 0.2% for radiotherapy.

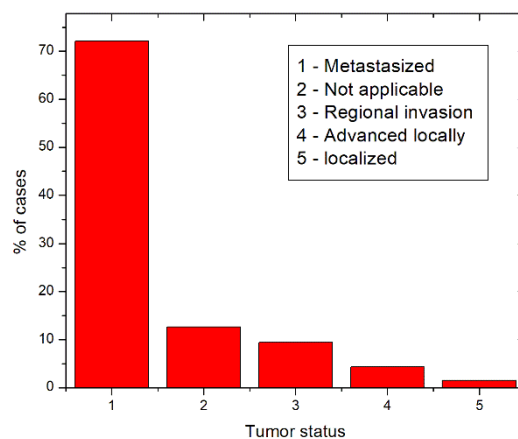


Fig. 2: Tumor status.

It was found that 54.2% patients had an Eastern Cooperative Oncology Group (ECOG) of four at the time of admission, 29.4% of three, 11.5% of two, 4.7% of one, and 0.2% of zero. The median time between cancer diagnosis and death was 18 months. Of the individuals studied, 89.5% had received treatment for their cancer. The last treatment consisted of chemotherapy in 52.9% of the cases and 10.5% of the individuals had never undergone antineoplastic treatment. The median time elapsed between the last antineoplastic treatment and the date of death was 62 days.

The time elapsed between the date of the last treatment and recommendation to palliative care had a median of 39 days. Recommendation to palliative care occurred in 53.7% of the cases studied. However, 37.1% of patients entered palliative care and, of the patients who did not, 4.8% of the total received palliative care in the service of origin. Only eleven cases for recommendation to palliative care took place before the treatment. The median time between recommendation for palliative care and access to it - in the different services such as hospitalization, home support or outpatient consultation - was 14 days. With regard to entry into care - also in the different areas - this was a median of 14 days from the patient's death. When the patient died in palliative care, it lasted a median of 10 days.

In short, a median of 27 days elapsed between the date of recommendation for palliative care and the patient's death.

In patients under 65, the median time between the last treatment and death was 71 days and between recommendation and death was 22 days. In those aged 65 and over, these medians were 101 and 26, respectively. These differences were statistically significant. There were no statistically significant differences between the sexes. When analysing the trend towards recommendations for palliative care according to the different specialties, it can be seen that the oncohematology specialty is the one that refers the lowest percentage of its patients for palliative care, despite the fact that most patients are admitted for symptomatic control, supportive treatment or terminal care.

However, the study found no statistically significant differences between the periods between the last treatment and death and between recommendation to palliative care and death for haematological patients compared to those affected by solid tumors. It is worth noting that only six patients in the sample had entered a palliative care service. There were 71.1% patients who died peacefully, mainly as a result of the nursing notes at the time of death regarding the patient's general condition and whether or not SOS medication was administered.

IV. Discussion

Research in the field of palliative care focuses mainly on individuals with cancer [4]. This study was carried out in a cancer hospital in order to test and identify the real components of palliative care provided and received. It has been found that, despite the development of palliative care resources, recommendations are still late and their use is still inadequate [5,6]. This is due to the fact that recommendation to palliative care is seen as recognition of the loss of hope, despite knowing that basing hope only on survival will only increase suffering and the very hopelessness of a full life [5]. In addition, there is some confusion over the terminology surrounding palliative care, which should not be considered strictly terminal care, but rather specialized and competent care in terms of quality of life, symptom control, patient autonomy, communication and continuity of integrated multidisciplinary care [5]. This study reinforced these premises, as it found that of the individuals studied, only just over half (47.3%) were referred for palliative care, and the time between recommendation for palliative care and death had a median of just 26 days, and 14 days between entering care and the patient's death.

A crucial point to note is that the median is 14 days between recommendation and access to palliative care, which is far too long given that recommendation occurs so late and close to the end of the patient's life.

In fact, medicine is almost exclusively concerned with curing disease and prolonging life, to the detriment of quality of life and alleviating suffering, with the latter only coming into consideration when the former has been exhausted and death is imminent [7]. However, this division results in the provision of more aggressive and costly care, and an increase in avoidable suffering throughout the course of an advanced illness [8]. Costs rise and care loses quality when the possibility of death, end-of-life choices and the transition to the prospect of dying are not considered in the discussion, essential aspects in the ideal planning of the care strategy to be provided to the patient [9]. In the study by Temel et al, the aggressiveness of end-of-life care was defined as chemotherapy in the 14 days prior to death, admission to a palliative care service three days or less before death, or lack of admission to a palliative care service [10]. The median time elapsed between the last treatment for the disease and the patient's death in this study was 58.5 days. The median length of stay in palliative care before death was 8 days, which is acceptable from the point of view of the purpose of the care. The period surrounding the patient's death was investigated in the medical and nursing records, reflected in the person's general condition at the time of death and whether or not rescue medication was administered for uncontrolled symptoms. A peaceful death was considered to have occurred in 72.1% of patients, and patients who received palliative care had more cases of death considered peaceful compared to those who did not receive palliative care.

This reinforces the need for health professionals to be trained in palliative care, since even with the growing sub-specialization in palliative care and geriatrics, it will still be general practitioners who provide most of the services in this area [4].

V. Conclusions

Modern medicine has contributed to an increase in the number of people living with chronic illnesses, which requires us to look into the specifics of palliative care¹. This study found that recommendation to palliative care occurred in just over half of the patients who died in hospital, meaning that although palliative care is available, there is still a large percentage of patients who do not benefit from it. The median time between cancer diagnosis and death was 18 months; between the last antineoplastic treatment and the date of death was 62 days; between recommendation and access to palliative care was 14 days; between entry into care and death was 14 days; and between the date of recommendation and death was 26 days. The median length of stay in palliative care until death was eight days. Patients under 65 had a shorter period between their last treatment and death, and between recommendation and death, compared to those aged 65 and over. There were no statistically significant differences between the sexes and between haematological and non-haematological patients. Patients who received palliative care had more cases of death considered peaceful, compared to those who did not. Providing palliative care requires healthcare professionals to apply skills that are not traditionally taught in medical schools, such as communication, which is a core skill in palliative medicine and for which there is little guidance, symptom management beyond pain or even pain syndromes, spiritual distress and complicated grief [10]. It is crucial to introduce more of these issues into medical and nursing training, especially undergraduate formation. Recognizing the pertinence of supportive treatment in the field of oncology, guidelines have been established on the management of a variety of issues. However, prospective studies are still needed to establish the most appropriate time for the first palliative care consultation during the course of the illness [11]. In order to better understand the global reality [9] regarding palliative care, it would be pertinent to involve more hospitals. It would also be interesting to extend research in the future into palliative care to pathologies other than cancer, given the importance of this approach in the management of any life-threatening illness.

References

- [1]. Eti S. Palliative care: an evolving field in medicine. *Prim Care Clin Office Pract* 2011;38:159–171.
- [2]. WHO - definition of palliative care: <http://www.who.int/cancer/palliative/definition/en/>
- [3]. Payne S, Leget C, Peruselli C, Radbruch L. Quality indicators for palliative care: debates and dilemmas. *Palliat Med* 2012;26(5):679-680.
- [4]. Lorenz C, Lynn J, Dy S, Shugarman L, Wilkinson A, Mularski R, et al. Evidence for improving palliative care at the end of life: a systematic review. *Annals of internal medicine* 2008;148:147-159.
- [5]. Gaertner J, Wolf J, Voltz R. Early palliative care for patients with metastatic cancer. *Curr Opin Oncol* 2012;24:357-362.
- [6]. Kelley A, Meier D. Palliative care – a shifting paradigm. *N Engl J Med* 2010;363;8:781-782.
- [7]. Morrison R, Meier D. Palliative care. *N Engl J Med* 2004;350:2582-90.
- [8]. Davis MP, Bruera E, Mrganstern D. Early integration of palliative and supportive care in the cancer continuum. *Am Soc Clin Oncol Educ Book* 2013;2013:144.50.
- [9]. Smith T, Hillner B. Bending the cost curve in cancer care. *N Engl J Med* 2011;364;21:2060-2065.
- [10]. Temel J, Greer J, Muzikansky A, Gallagher E, Admane S, Jackson V, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363:733-742.
- [11]. Osta BE, Palmer JL, Paraskevopoulos T, Pei BL, Roberts LE, Poulter VA, et al. Interval between first palliative care consult and death in patients diagnosed with advanced cancer at a comprehensive cancer center. *J Palliat Med* 2008;11(1):51-7.