

# Early Referral to Palliative Care: The Rationing of Timely Health Care for Cancer Patients



## Referenciação Precoce para Cuidados Paliativos: O Racionamento dos Cuidados Eficientes de Saúde em Doentes Oncológicos

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### ABSTRACT

Palliative care in oncology is an interdisciplinary approach, centered on patients and their families, carried out along the course of neoplastic diseases, based on symptom control, assertive communication and shared decision-making. Although clinical guidelines recommend a holistic intervention, early integration of palliative care into traditional oncological treatment, research shows a great delay in referral of patients, restricting palliative care to end-of-life care. Why does there seem to be a rationing of the early referral, sometimes in violation of human dignity? To a large extent it has to do with lack of knowledge, training and education of health professionals about palliative care and the techniques to deal with the process of death and dying. Several studies have demonstrated the benefit of integrating palliative actions into the routine of active cancer treatments, not only in terms of effective control of physical and psychological symptoms, but also in terms of overall quality of life, patient and family satisfaction, health care costs and survival in some cases. It is necessary to take measures that encourage oncologists to obtain further training in palliative care, as a formal, compulsory internship, integrated in their specific training program. This way, a new generation of physicians will surely change the lives of cancer patients, and their families, integrating — without disproportionate rationing — oncology and palliative medicine.

**Keywords:** Delivery of Health Care, Integrated; Palliative Care; Patient Care Team; Referral and Consultation; Terminal Care

### RESUMO

Os cuidados paliativos oncológicos constituem uma abordagem interdisciplinar, centralizada no doente e nas suas famílias, realizada ao longo da trajetória das doenças neoplásicas, alicerçada no controlo de sintomas, na comunicação assertiva e na tomada de decisão partilhada. Apesar de as normas de orientação clínica aconselharem uma intervenção holística, integrando precocemente os cuidados paliativos no tratamento oncológico tradicional, a investigação demonstra um grande atraso na referenciação dos doentes, restringindo os cuidados paliativos no fim de vida. Por que razão parece existir um racionamento da referenciação precoce, atentatório da dignidade humana? Em grande parte, é por falta de conhecimento, treino e educação dos profissionais de saúde sobre os cuidados paliativos e as técnicas para lidar com o processo de morrer e a morte. Vários estudos demonstram o benefício da integração de ações paliativas na rotina dos tratamentos oncológicos ativos, não só a nível do controlo eficaz de sintomas físicos e psicológicos, mas a nível da qualidade de vida global, da satisfação do doente e da família, dos custos dos cuidados de saúde e também da sobrevida, em alguns casos. É necessário tomar medidas que encorajem o oncologista a obter mais formação em cuidados paliativos, como um estágio formal, obrigatório, integrado no seu internato de formação específica. Deste modo, uma nova geração de médicos mudará seguramente a vida dos doentes com cancro, e suas famílias, integrando — sem racionamento desproporcionado — oncologia e medicina paliativa.

**Palavras-chave:** Cuidados Paliativos; Cuidados Terminais; Encaminhamento e Consulta; Equipa de Assistência ao Doente; Prestação Integrada de Cuidados de Saúde

Palliative care (PC) in oncology is an interdisciplinary approach, centered on patients and their families, carried out along the course of neoplastic diseases, based on symptom control, assertive communication, and shared decision-making.<sup>1</sup>

The current guidelines proposed by Oncology Societies — both European<sup>2</sup> and American<sup>3</sup> — advise a holistic intervention, promptly integrating PC in the traditional treatment of cancer patients. However, research shows a considerable delay in the referral of these patients, restricting PC to end-of-life care.<sup>4</sup>

Referral to PC does not translate into an immediate admission of a patient to a specific unit; it may represent

an outpatient follow-up, at home or at an outpatient clinic. Follow-up in PC can be recommended in the presence of: uncontrolled acute physical symptoms (pain, dyspnea, vomiting, delirium, suicide risk); aggravated chronic physical symptoms (anorexia-cachexia, anxiety and depression, general decline of function); psychosocial issues (advance care directives, financial difficulties); existential and spiritual matters (meaning of life, hope, legacy and dignity, religiosity and spirituality, total well-being).<sup>4</sup>

Why does rationing of early referrals, sometimes in violation of human dignity, occur? Why does PC massively reach, for instance, patients with a terminal illness, cognitive impairment, or social exclusion?

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Why not offer a choice of this palliative 'fast track' to cancer patients, early in the trajectory of their disease? Why does an oncologist initially ask for the 'opinion' of radiation oncologists, surgeons, radiologists, pathologists, among others, actively involving them in the clinical management of a patient with cancer while overlooking the early opinion of a PC specialist? Why are not PC physicians included in a formal initial multidisciplinary oncology team? Do oncologists see themselves as PC specialists? In some countries this specialty belongs to a different residency and board. In Portugal, an oncologist has no automatic competence in palliative medicine.

Is the option of PC left in hiding because of a triumphalist model of approach by means of which its upfront presentation to patients would anticipate an unsuccessful possibility of cure?

Several questions can be raised with the answer including lack of knowledge, training and education of healthcare professionals about PC and the techniques to deal with the process of death and dying. The negative connotation that the term 'palliative' implies, coupled with the lack of training in clinical communication skills and the fear of conveying the prognosis, can lead to hopelessness for cancer patients and an aversion to this type of care. Oncologists should fight this tendency with an inclusive attitude and be responsible for precociously presenting the patient to a PC team.

In fact, we found two methods of PC referral in oncology: the one motivated by the physician and the automatic one. The first method implies that the oncologist is able to recognize, in patients with advanced cancer, the need for specialized PC; following-up the simpler cases in his/her

oncology consultation or hospitalization, in an effective and objective way. For the most complex cases, from the clinical and psychosocial point of view, the early integration of oncology and PC improves the outcome of patients.<sup>5</sup> Automatic referral is based on a set of predefined criteria that include diagnosis and prognosis, performance status, refractoriness of treatment, complexity of the symptoms, etc.<sup>6</sup> We believe that the ideal method of PC referral lies in an attitude that unifies the two methods, based on personal and clinical knowledge of the patient (measured individual needs) and the demonstrated benefit of an early referral (defined medical criteria).

Several studies have demonstrated the benefit of integrating palliative actions into the routine of active cancer treatments, not only in terms of effective control of physical and psychological symptoms, but also in terms of overall quality of life, patient and family satisfaction, health care costs and survival in some cases.<sup>5,7-9</sup>

It is necessary to take measures that encourage oncologists to obtain further training in PC<sup>10</sup> as a formal, mandatory internship integrated in their specific residency program. This internship would provide the necessary foundations in PC for the oncologists to offer their patients, knowing when to refer complex cases to a PC specialist. This way, a new generation of physicians will surely change the lives of cancer patients and their families, integrating — without disproportionate rationing — oncology and PC. Both should be combined early in the process in order to benefit patients suffering from cancer, actively prescribed, and always in the wake of *legis artis*.

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