



## Letter to the Editor

# “There’s nothing left to do!”: the interface between Hematology and Palliative Care



Historically, the integration of palliative care in Hematology has represented a struggle, mainly due to the incorrect understanding of what palliative means. Any discussion should always start with a clear definition of what exactly palliative care is in addition to its goals. In this sense, the term “palliative” derives from the Latin *pallium*, cloak that the knights used to protect themselves from storms along the paths they traveled. Etymologically, palliate means to protect. The World Health Organization (WHO) defines Palliative Care as: “An approach that aims to improve the quality of life of patients and families in the context of a serious and life-threatening disease through prevention, relief of suffering, early identification and flawless treatment of pain and other symptoms and physical, psychic, social and spiritual problems”.<sup>1</sup>

The term “palliative care” is often incorrectly used as a synonym for an end-of-life care or when there are no longer treatment options to modify the underlying disease. However, engaging in palliative care does not indicate that the patient is dying and in no way means that the hematologist is giving up on the patient. “Palliative care” does not refer to a specific location or stage of the illness but describes a philosophy of care. Undoubtedly, end-of-life patients are an important population that palliative-care specialists work with. But, specialty-level care is available upstream, earlier, and earlier in the trajectory of the disease, including at diagnosis of a serious and potentially fatal disease, regardless of the stage of the disease. Physicians perpetuate misconceptions regarding the palliative care of their patients, who do not know what palliative care is and do not have enough information to form their own opinion. A public opinion showed that most lay Americans have never heard the word “palliative” and that they were unaware of the meaning of the term. Furthermore, the inquiry showed that when people learn more about palliative care, they are very interested in receiving this specialized medical care for their loved ones or for themselves.<sup>2</sup>

Oncohematologists are used to taking care of patients independently; in other words, the multidisciplinary involvement (surgery, radiotherapy, among others), which is typical in solid tumors, is not the norm in the treatment of

hematological diseases. This level of independence and autonomy leads to a strong sense of ownership, paternalism, and a desire to meet all the patient’s needs. Dr. LeBlanc, specialist in Hematology and Palliative Care, said: “When a referral to a palliative-care clinician is needed, it will be important for hematologists to understand the benefits and the reasons why that referral is happening. Hematologists have to be able to acknowledge that they cannot be everything to every patient, and they may need help. A palliative-care specialist provides an extra layer of support that can help your patient feel better, live better, and tolerate treatments better, while the hematologist focuses on treating the cancer. Together they can help make the experience as good as it can be.”<sup>3</sup> In the article titled “Early integration of Palliative care in Hematology: An urgency for patients, a challenge for physicians”, a review of medical literature also published in this issue, by Freitas et al.<sup>4</sup>

Palliative care works with an interdisciplinary team consisting of doctors, nurses, psychologists, nutritionists, physiotherapists, social workers, chaplains, and pharmacists. One of the goals of palliative care is to assess a patient’s total pain experience, approaching pain from a multidimensional perspective. By making a complete history of the impact on the physical, psychosocial, quality of life and spiritual domains, it is possible to reduce pain to a more tolerable and acceptable level for the patient.<sup>5</sup> Among other objectives are to assess patient’s understanding of their disease, treatment options and the likely course of the disease; identify questions and concerns patients may have regarding their condition, treatment and/or prognosis and facilitate communication with the hematologist. Most palliative care offered to cancer patients is provided by oncologists themselves, what some call “primary palliative care” or “general palliative care”. However, there are patients with more complex needs who can benefit from specialized services. Additional work is needed across oncology to increase skills in primary palliative care and define which population will benefit from additional information. Specialty-level involvement in palliative care can be episodic and intermittent or, instead, be continuous,

longitudinal, and co-managerial. Hematologists, when referring their patients, should feel comfortable and know what to expect from the specialist in palliative care.

Patients with hematologic malignancies experience a burden of physical and psychological symptoms comparable to or greater than patients with advanced solid tumors, including pain, mucositis, dyspnea, fatigue, nausea, constipation, and diarrhea. Data suggest that many patients with hematologic malignancies do not receive high-quality care at the end of life and, despite their significant needs, rarely use palliative-care services compared to patients with solid tumors.<sup>6</sup> Unlike solid tumor oncology, where a more complete integration of palliative care began more than a decade ago, the field of hematologic malignancies often lacks a clear transition from the curative phase to a more palliative phase. The identification of the end-of-life phase due to the continuing potential of cure in patients with advanced disease and rapid clinical decline near death are challenging. Patients are often hospitalized during the last month of life and die there, and/or receive chemotherapy, blood products and antimicrobials during the last week of life. Patients place great trust in their hematologists and as a result, some may be reluctant to reveal the full extent of their symptom burden or their hopes and fears regarding treatment, believing that this may alter the therapeutic strategy or occasion an immediate discussion of “bad news”.<sup>4</sup> However, patients may share information differently with palliative-care providers with the feeling that they are in a “low risk” environment. As demonstrated in studies, palliative-care consultations have distinct characteristics from oncology consultations, and evidence suggests that what patients tell their oncologist is very different from what they say to their palliative care specialists.<sup>7–9</sup> Thus, the roles of each clinician are complementary in the care of patients with advanced cancer and the information obtained can be grouped and shared to more fully address the needs and concerns of a given patient.<sup>10</sup> A late referral limits the scope of involvement in palliative care to only terminal care and neglects benefits that may be offered previously.

Despite being called benign diseases by hematologists, sickle cell anemia, hereditary anemia, aplastic anemia, paroxysmal nocturnal hemoglobinuria, hemophilia, among others, present limiting symptoms, high symptomatic burden, greater number of comorbidities related to the underlying disease, psychological disorders, and impact socioeconomic status, casting them as an eligible group for palliative care.

Studies in bone marrow transplantation have been carried out and show that early palliative care before admission for stem cell transplantation is feasible and acceptable. Furthermore, models of collaboration between teams are associated with clinically and statistically significant reductions in hospitalization time length and trends in reducing transfers to intensive care units, providing multidisciplinary education in the wards. In a randomized study involving patients undergoing bone marrow transplant treatment associated or not with palliative care, Areej El-Jawahri et al.<sup>11</sup> found that those who received palliative-care team visits had a lower symptom burden, better quality of life, less anxiety, and less depression during hospitalization; this improvement was sustained over the subsequent three months. Palliative-care specialists spent most of their time conducting interviews with patients,

discussing symptom management, or coping skills, and building a relationship with the patient.<sup>11</sup>

Therefore, Hematology is a broad and complex medical specialty, comprising heterogeneous diseases with different prognoses, and in constant change with the introduction of new targeted therapies and immunotherapies. While these treatments can improve disease-free survival and/or overall survival of patients who receive them, they can also have significant side effects where palliative care can improve management rather than replace standard care.<sup>12</sup> As Dr. LeBlanc states: “it is not a ‘one or the other’ perspective; and yes “and with”. It is important to explore and identify the values and goals of each patient and given the individualized and personalized context, examine the possible treatment options at each stage of the disease.”<sup>10</sup>

The creation of the Palliative Care Committee by the Hematology, Hemotherapy and Cellular Therapy Brazilian Association (ABHH) is an essential opportunity to disseminate the concepts of Palliative Care, providing continued education to health professionals, encouraging studies in different areas, such as validation of prognostic tools, symptom control, amongst others. Thus, we believe that many of the obstacles can be overcome and that patients, their caregivers, and health professionals will all benefit from the expansion of care.

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## Conflicts of interest

The authors declare no conflicts of interest.

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