



# Palliative Care in the Emergency Department: Inequality Leading to Additional Challenges and Opportunities

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## Editorial

Palliative care is an interdisciplinary medical specialty in which the purpose is to alleviate suffering and improve the quality of life of people in all stages of a disease that threatens the continuity of life. This approach is people-centered and seeks to respect the values and desires of patients and families [1]. The International Association for Hospice & Palliative Care organized a task force to review the concept of palliative care, which resulted in a conceptual update that broadened the scope of palliative care, and the following was published in 2020: "Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their care givers" [2].

It is assumed that 56.8 million people require palliative care each year. Of these, only 14% will have this need met [3]. However, the global need for palliative care will continue to grow, mainly because of the ageing of populations and the rising burden of noncommunicable diseases. Most palliative care services are offered in high-income countries, although the greatest need is in low-income countries. It is noteworthy that 78% of patients who need palliative care are in low and middle-income countries, where palliative care services are usually not integrated into national health systems, which restricts patients' access. Furthermore, these countries are also affected by misinformation about the role of palliative care services, underfunding, and social and cultural aspects about death [3]. The 2018 Lancet Commission Report describes that more than 80% of people who died in 2015 with serious health-related suffering were from resource constrained regions and the vast majority did not have access to palliative care and pain relief. This percentage amounts to over 20 million people [4]. For these patients, care is poor or entirely unavailable [5]. In addition, lack of knowledge about the evolution of the disease restricts autonomy for decision-making.

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Some specific issues hinder the development of palliative care services around the world as strong taboos against talking about death, which impairs the establishment and acceptance of end-of-life care services [6,7]; inadequate availability of analgesics (both opioids and nonopioids) [8]; barriers to access pain relief medication due to strict policies, administrative limitations, and lack of education on safe prescription of pain medications worldwide.

As the life-threatening disease progresses, the frequency of admission of these patients to the Emergency Department (ED) increases [9]. Common reasons that lead palliative care patients (or people who should be under palliative care) to seek ED are inadequate symptoms control, malfunction or loss of devices such as tracheostomy or gastrostomy tube and antagonistic and distressing feelings towards the imminent loss of life (fear, stress, conflicts between patients and caregivers, insecurity regarding the suspension or contraindication of treatments) [10]. Situations like these require skills from ED professionals to address immediate needs, such as to control symptoms and complications and to guide subsequent care, considering the values and preferences of patients and families [11]. In addition, the hospitalization decision and the choices regarding life-sustaining interventions are often made at ED. Patients' impaired access to palliative services, which should be done in primary health care [12], also leads them to the ED, seeking control of symptoms and relief of suffering. Thus, the integration between emergency medicine and palliative care for the benefit of the patient is essential [13].

However, many challenges are observed. The inadequate physical structure of overcrowded EDs, without privacy, and full of overworked professionals, makes it difficult to approach the patient and the family in a way that is compatible to their needs. The lack of bond between the patient and the ED professionals is an additional issue that makes end-of-life conversations and care planning

more complex and delicate.

Patients that experience unequal access to palliative care are unaware of the evolutionary stages of the disease, which can generate an unrealistic expectation regarding the prognosis. Access inequality means that fundamental aspects of palliative care have not even been presented to the patient, such as life expectancy, progressive impairment in quality of life and the importance of living will and advanced directives. It is not expected that the patient will be able to make such important decisions in an ED conversation, in a situation of insecurity and deep suffering. Therefore, it remains for ED professionals to approach delicate aspects even in such an adverse situation. Consequently, this model, while shifting care from the primary health care setting to the ED, also transfers to an uncomfortable setting, conversations and decisions that should be taken carefully, in a welcoming environment, by a specifically trained multidisciplinary team.

Suffering may be more related to the meaning of pain than to its intensity, and a conversation between a patient and a clinician reveals much more than the physical pain, supposedly measurable in scales [14]. That is why palliative perspective in the ED, for those patients that do not have access to full palliative care, requires even more elaborate skills. Although within a busy environment, communication is a fundamental skill that cannot be neglected. Sensitive listening, empathy, clarification, and availability are as fundamental as opioids. This is an exercise in rational compassion. Regardless of the protocol used to communicate bad news, the clinician must be an active information mediator, supporting the shared development of a care plan, respecting patient and family members' beliefs and preferences, but also providing knowledge on best practices.

Improving access to palliative care requires multidimensional measures that involve greater clarification to the population about advance directives, investment in professional education, discussions about orthothanasia and dignity at the end of life. Changing this reality is slow and long-term. While there are no ideal conditions for the vast majority of people who need palliative care, the ED becomes an opportunity to link the palliative emergency patient to continuous palliative care. This early integration can substantially improve patient care [15,16].

Even if the disease can no longer be cured, comprehensive care for patients and their families can never fail. And the best way to play this role is by listening, even if the noisy and tumultuous environment makes this task challenging. Sensitive and quality listening remains the best way to know needs and address them, with the purpose of strictly complying with what palliative care proposes.

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