

## RESEARCH ARTICLE

## Palliative Care: It's Time to Clarify Key Concepts and Definitions

René Robert<sup>1\*</sup>, Michel Goldberg<sup>2</sup>

<sup>1</sup>Université de Poitiers, CHU de Poitiers, service de Médecine Intensive Réanimation, F-86000 Poitiers, France

<sup>2</sup>University of La Rochelle, CNRS, LIENSs, F-17000 La Rochelle, France

**\*Corresponding Author:** Rene Robert, Service de Médecine Intensive Réanimation CHU Poitiers 86000 Poitiers, France, Tel +33549444367, Fax +3349443852, E-mail: rene.robert@chu-poitiers.fr

**Citation:** René Robert, Michel Goldberg (2023) Palliative Care: It's Time to Clarify Key Concepts and Definitions. J Palliat and Med Care 2:101

### Abstract

Palliative care is a necessary and often crucial component for some patients with severe disease during their medical course. It can be used at any stage of a severe chronic illness and the need for it grows as the disease progresses. While strategy and therapeutic intensity differ according to this evolution, the only term used is "palliative". It seems necessary to clearly understand when the patient is approaching the end-of-life stage in order to adapt the management modalities particularly in an intensive care unit (ICU) setting. The new semantic approach we are proposing could help to overcome ambiguities of terminology surrounding palliative care and to better characterize the phase of palliative care dedicated to end-of-life support.

**Keywords:** Palliative; End-of-Life; Quality of Life; Withdrawal Life Support; Lexical Approach

### Abbreviations

ICU: intensive care Unit

QOL: quality of life

## Background

Palliative care has emerged as a necessary and often crucial component in the medical course of many patients, particularly in cancer, neurodegenerative diseases and, advanced heart, respiratory or liver failure [1-3]. To carry out palliative care, specific units have developed over the world with various names: palliative care, hospice care and, mobile palliative care units, while some palliative care beds have been included within general care units. In the ICU, appropriate goals should be established according to the patient's condition, prognosis, and value. However, the single word "palliative" is uniformly used, whatever the stages of disease evolution, and the specific therapeutic avenue that may remain possible. Palliative care is often confused with end-of-life care, and this conflation under-values the benefits of palliative care for seriously ill patients who are not imminently dying – such as symptom management, psychosocial support, and advance care planning. In contrast to end-of-life care, palliative care is provided in concert with curative or restorative treatments and in coordination with other care teams in an integrated, approach designed to optimize quality of life and to ensure patient as well as family-based psychosocial support, regardless of disease prognosis or treatment goals. In case of acute altered organ function, the palliative patient "label" can lead to therapeutic withholding or withdrawal of life support strategies, at times even entailing refusal of ICU admission. It would make sense to use more nuanced and discriminating terminologies to clarify different clinical situations. Additionally, many commonly used terms in palliative care are poorly defined and a lack of definitional clarity related to several concepts and terms is well-recognized, as is a need for consensus in definition of palliative care [4]. We recently proposed a new and original strategy helping to bring clarification for clinical situations [5]. The aims of this review are to analyze the different meanings of the term "palliative" and to discuss the semantic analysis and lexical approach leading to better identify phenotypic profile linked to different level of care.

### The Same Word Covers Three Different Stages of the Disease

The term "palliative" reflects a clinical situation without prospect of complete recovery from the illness. It is defined as treatment that alleviates the symptoms of a disease without acting on its cause. Palliative care integrates the management of physical and psychological pain and other symptoms that are bothersome to the patient. In several clinical situations, it begins early in the patient's life when his prognosis is still good; this initial stage implies prolonged life expectancy and normal or sub-normal quality of life (QOL). Moreover, early referral to palliative care has been shown to improve quality of life and survival in patients with cancer [5-8]. The following two stages entail clinical limitations. In the second, end-of-life is approaching: physical condition is altered, activities are reduced and the patient may need partial assistance with some daily living activities. Mental capacities are generally close to normal. QOL is limited but may be still considered acceptable based on the patient's self-evaluation. At this stage of the disease, curative care has been intensified but is reaching the end of its intended effect and the palliative care has increased. When chemotherapy is offered, it is referred to as "palliative" chemotherapy or sometimes as "terminal palliative chemotherapy". Its objective is no longer a reduction in tumor mass, but a possible slowing of the kinetics of tumor progression. The real benefit of these chemotherapies on the quality of patients' end-of-life has been discussed [9]. Lastly, when end of life is near, physical capacities are extremely poor, QOL is deeply altered and the patient needs assistance with all daily living activities. Overall distinction between these three stages is associated with prognosis of diseases, additional co-morbidities, frailty scores, QOL evaluation and psychosocial performance. However, the boundary between the different stages is not clear, and the physician or healthcare team need to decipher the grey areas between them (Figure).

Figure 1



**Figure 1:** Palliative care during the three stages of severe chronic illness

### Which Management Strategy Should Be Adapted to The Clinical Situation of a Palliative Care Patient?

Taking the three stages of the patient's course outlined above, we can schematically define an appropriate management strategy. During the first phase, the patient should be considered as unrestricted and benefit from unlimited treatment. If necessary, the patient can be admitted to an Intensive Care Unit (ICU) with full code management. When the patient is approaching the end of life, treatment may be withheld. Given complications, the probability of dying soon is high, but there remains hope for survival of the patient with the goal of restoring a satisfactory QOL in the short, medium and occasionally long term. As an example, patients admitted to ICU for respiratory distress with a do-not-intubate order may benefit from non-invasive methods of oxygenation or ventilation [10]; in this group, hospital and one-year mortalities are approximately 50%, and 70% respectively, depending on the type of pathology under consideration [10]. Finally, at the end-of-life stage, specific treatments are withdrawn, and the expected outcome is death of the patient. The priority is to ensure the best possible quality of dying in accordance with the patient's wishes, integrating support for family and friends. These patients should not be admitted to ICU or should have their life support treatment withdrawn. However, several studies have shown that patients with chronic life-threatening illness or frailty continue to receive non-beneficial treatments at the end of life [11,12]. For example, around 20% of cancer patients receive chemotherapy within 14 days of death [13,14]. Despite recommendations by palliative care specialists for the co-management of patients, there has been only little improvement over the past two decades [12,15]. In one recent study inappropriate interventions near the end-of life stage reached 34% of cases [16]. Besides potentially excessive interventions in dying patients, a palliative label can lead to therapeutic withholding or withdrawal of life support strategies, at times even entailing refusal of ICU admission. Since ambiguities in the patient classification may partially explain such discrepancies, a more precise framework appears warranted.

### More Discriminating Terminologies to Clarify Differing Situations

Following this analysis, the fact remains that the term "palliative" is used for patients who may correspond to three strategies corresponding to different intentionality and therapeutic options. The use of a differentiated terminology to clarify these situations seems necessary.

A distinction between the terms "palliative" and "hospice" care has been proposed. Hospice care designates situations where life expectancy is reduced and the patient is encouraged to express his wishes regarding treatment limitations, for example by refusing resuscitation after cardiac arrest or intensive care admission [8].

Numerous additional terms have been used to more closely correspond to the clinical condition of the palliative care patient: "comfort", "supportive", "best supportive care" or "hospice care" [17-19]. However, several different definitions have been used and whatever the term, confusion in terminology persists and no semantic consensus has been reached [18,20,21]. The definition for supportive care has been closely associated with cancer patients [22], and the superlative "best" has been added without any readily apparent justification [23]. Hospice care has been discussed in a largely American context and cannot be easily transposed to other countries. Moreover, the term "hospice care" may in some case to be associated with fear [20]. Heterogeneity is also found in the terminology used to characterize the end-of-life stage: "end-of-life", "terminal illness", "actively dying" and corresponding ways of treating the patient: "care of the dying", "terminal care", "transition of care", "quality-of-life care" [19]. Moreover, the implied duration of remaining life for end-of-life patients can range from a few days to 6 months, highlighting the confusion surrounding the terminology and the ambiguities regarding the nature and intensity of the care to be provided. As for "supportive care" it has been gaining popularity as a designation for "palliative care" programs insofar as it is less likely to provoke anxiety [21, 24]. Hui et al. proposed a conceptual framework highlighting the overlapping of the terms hospice care, palliative care and supportive care [20]. In this model, "hospice care" is part of "palliative care," which in turn, is part of "supportive care." The authors also suggested another conceptual framework toward understanding "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care" [19]. In this model, end of life, terminally ill, and terminal care periods are synonymous and apply to patients with progressive disease with at most a few months of expected survival. The authors separated actively dying (patients with days of survival) from end of life, terminally ill or terminal care period which would indicate months of survival [19]. Using in this approach, a combination of the two models is necessary to cover overall field of palliative care, and the ambiguities and overlapping of the terms underlined by the authors are not fully clarified. In summary, the reasons underscoring the need for a new model are summarized in table 1.

Wide range of current definitions
Significant overlaps within the current definitions
Ambiguities induced by "Palliative care"
Unsuitable pejorative label for some patients (early palliative care)
Confusion between stage of disease and level of care
Confused with end-of-life care
Terms specifically used only in some countries (hospice care)
Confusion between stage and care
Persisting ambiguities with the terms of hospice, supportive and best supportive care
Pejorative/aggressive vision of "terminal", a word provoking anxiety or brutality for the patient and his family
Variations in the correlation between terminal illness and expected survival

**Table 1:** The reasons that suggest the need for a new framework for palliative care

## Semantic and Lexical Approach

Since up until now, no single word has been satisfactory, it is crucial to identify one or more words that can consensually clarify the patient's care pathways. The terminology should apply regardless of the pathology concerned.

## Distinction Between Characterization of Care and Stage of the Disease

Care refers to a therapeutic objective that can be preventive or directly contribute to clinical improvement of the patient. Stage refers to the evolution of the disease according to various kinetics. The term palliative "care" can be applied to the patient without prejudging disease prognosis, whereas palliative "stage" corresponds to a pejorative prognosis for the patient.

## Lexical Approach

To overcome the historical ambiguities and to improve the description of a patient's course, and to refine the semiology of clinical situation we have decided to propose new terms [5]. We are suggesting a framework for palliative management as a way of more precisely characterizing the nature of palliative care for the seriously ill (table 2).

	Temporality	General condition physical abilities	Goals of Care	Admission in ICU
Stage 1 Corrective	Extended life expectancy with good expected quality of life	Preserved or can be standardized	Curative unlimited	Yes
Stage 2 Meliorative	Estimated end of life less than 6 months and altered quality of life	Altered	Sustaining quality of life	No, or yes by withholding life support treatment
Stage 3 Palliative	Entering the end of life; death expected within a few days to a few weeks	Deeply altered	End-of-life support	No

**Table 2:** New proposals to characterize palliative management [5]

The proposed terms were based on four criteria. First, the terms should be simple and understandable by non-specialized professionals. Secondly, they should identify the three distinct stages of palliative way with correspondingly different management. Thirdly, the direct lexical field of death or pain should be avoided so as to limit patient and family concern. Finally the terms should not be euphemizing, but adapted to the palliative care.

The first stage is addressed to patients requiring early palliative care with the term "corrective" indicating that everything should be done to improve the clinical status of a patient with expected good prognosis and QOL. For the second stage, we suggest the term "meliorative". Seldom used, it is opposed to "pejorative". It comes from the Latin *meliorare*, which means to improve, presenting the designated idea or object in a favorable light. It could be applied to the need to maintain the best possible QOL in situations where that is the objective. There is no longer any prospect of recovery or substantial expected improvement in the patient's condition. Patients benefit primarily from symptom management such as nutritional support, psychosocial support, mobilization and care aimed at improving their immediate well-being. For the third and ultimate stage, we suggest a new word "palliative" to characterize palliative care focused on end-of-life support. This neologism would apply to patients whose death is expected within a few days or a few weeks without any curative treatment or vital support treatment, and for whom comfort care at the end-of-life is a priority. The term "palliative" can be considered as a lexical amalgam based on a common thematic sound; with this neologism, the general field of palliative care remains intact. Using this original new classification, it has been proposed to describe therapeutic targets according to this phenotypic approach helping to clarify clinical aims for the patient's care [24].

## Limitations

Better differentiated terminology aims a/ to help caregivers to formalize their intentionality and their goals for a patient's care and b/ to enable patients and families to understand and to accept the scalability of their illness. However, it will not replace the tasks that clinicians should perform to help patients and families cope with uncertainty; it will remain necessary to assume the uncertainty of prognosis and the emotional difficulties that ensue. It will also remain necessary to help patients and families to live in the here and now, according to the current clinical situation [25].

To overcome ambiguities and misunderstandings stemming from the multiply and perhaps overly used term "palliative", we have suggested a new semantically enriching approach including the word "meliorative" and the neologism "palliative" as a way of more precisely characterizing the nature of palliative care for the seriously ill.

This approach is not a theoretical exercise, but aims to relay a pragmatic clinical patient-centered approach. Such new proposals will need to be validated and adopted by the caregivers involved. Thus the next step will be to conduct prospective study using this new tool to assess the clarification in the patient's course.

## References

1. Allen LA, Stevenson LW, Grady KL, Goldstein NE, Matlock DD et al. (2012) Decision Making in Advanced Heart Failure: A Scientific Statement from the American Heart Association. *Circulation*. 125(1): 1928–52
2. Hui D, Bruera E (2015) Models of integration of oncology and palliative care. *Ann Palliat Med* 4: 89-98
3. Robinson MT, Holloway RG (2017) Palliative Care in Neurology. *Mayo Clin Proc* 92: 1592-601
4. Ferris FD, Bruera E, Cherny N, Cummings C, Currow D, et al. (2009) Palliative cancer care a decade later: accomplishments, the need, next steps -- from the American Society of Clinical Oncology. *J Clin Oncol Off J Am Soc Clin Oncol* 27: 3052-8
5. Robert R, Goldberg M (2021) Palliative, palliative or palliative? *Crit Care* 25: 203
6. Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AGK, et al. (2002) Do hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage* 23: 96-106
7. Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC et al. (2009) Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA* 302: 741-9
8. Kelley AS, Morrison RS (2015) Palliative Care for the Seriously Ill. *N Engl J Med* 373: 747-5
9. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S et al. (2010) Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363: 733-42
10. Azoulay E, Kouatchet A, Jaber S, Lambert J, Meziani F et al. (2013) Noninvasive mechanical ventilation in patients having declined tracheal intubation. *Intensive Care Med* 39: 292-301
11. Cardona-Morrell M, Kim J, Turner RM, Anstey M, Mitchell IA, Hillman K (2016) Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem. *Int J Qual Health Care J Int Soc Qual Health Care* 28: 456-69
12. Hill AD, Stukel TA, Fu L, Scales DC, Laupacis A et al. (2019) Trends in site of death and health care utilization at the end of life: a population-based cohort study. *CMAJ Open* 7: E306-15
13. Pacetti P, Paganini G, Orlandi M, Mambrini A, Pennucci MC, Del Freato A, et al. (2015) Chemotherapy in the last 30 days of life of advanced cancer patients. *Support Care Cancer Off J Multinatl Assoc Support Care Cancer* 23: 3277-80
14. Colombet I, Bouleuc C, Piolot A, Vilfaillot A, Jaulmes H, et al. EFIQUAVIE study group (2019) Multicentre analysis of intensity of care at the end-of-life in patients with advanced cancer, combining health administrative data with hospital records: variations in practice call for routine quality evaluation. *BMC Palliat Care* 18: 35
15. Ho TH, Barbera L, Saskin R, Lu H, Neville BA et al. (2011) Trends in the aggressiveness of end-of-life cancer care in the universal health care system of Ontario, Canada. *J Clin Oncol Off J Am Soc Clin Oncol* 29: 1587-91

16. Boddaert MS, Pereira C, Adema J, Vissers KCP, van der Linden YM, Raijmakers NJH, et al. (2020) Inappropriate end-of-life cancer care in a generalist and specialist palliative care model: a nationwide retrospective population-based observational study. *BMJ Support Palliat Care*. 12 (e1): e137-e145
17. Fallon M, Smyth J (2008) Terminology: the historical perspective, evolution and current usage--room for confusion? *Eur J Cancer* 44:1069-71
18. Hui D, Mori M, Parsons HA, Kim SH, Li Z, Damani S, et al. (2012) The lack of standard definitions in the supportive and palliative oncology literature. *J Pain Symptom Manage* 43: 582–92
19. Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M et al. (2014) Concepts and Definitions for “Actively Dying,” “End of Life,” “Terminally Ill,” “Terminal Care,” and “Transition of Care”: A Systematic Review. *J Pain Symptom Manage* 47: 77-89
20. Hui D, De La Cruz M, Mori M, Parsons HA, Kwon JH et al. (2013) Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks. *Support Care Cancer Off J Multinatl Assoc Support Care Cancer* 21: 659-85
21. Hui D, Bruera E. Integrating palliative care into the trajectory of cancer care (2016) *Nat Rev Clin Oncol* 13: 159-71
22. Cramp F, Bennett MI (2013) Development of a generic working definition of ‘supportive care.’ *BMJ Support Palliat Care* 3: 53-60
23. Cherny N (2011) Best supportive care: a euphemism for no care or a standard of good care? *Semin Oncol* 38: 351-7
24. Lemyze M, Dupré C (2022) High flow oxygen via nasal cannula: Palliative care and ethical considerations. *Rev Mal Respir* 39: 367-75
25. Smith AK, White DB, Arnold RM (2013) Uncertainty--the other side of prognosis. *N Engl J Med*. 368: 2448-50.