

# *What is so confusing about the term 'palliative'?*

## A review of palliative care definitions and their relevance on nephrology

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### Abstract

In palliative and end of life care, numerous terms can be found that might be understood in different ways by the patient, his/her relatives, doctors, nurses, and other health care professionals. Unfortunately, even commonly used and prognostically highly relevant terms such as *palliative*, *curative*, or *supportive*, bear numerous opportunities for severe misunderstanding. This is even more true for medical specialties that care for chronically (and therefore 'incurably') affected patients, like in nephrology.

This contribution analyses the respective palliative care definitions, their differences and discrepancies, and describes an 'early integrative' and needs-oriented palliative care approach that may help to overcome prognostic uncertainties that not seldomly prevent comprehensive support for severely affected patients.

### Introduction

*"This patient is not 'palliative'!"*

This statement can be heard in different clinical scenarios, including

- patients suffering from locally advanced or even metastasized solid cancer, receiving multi-modal anticancer therapies in 'curative' intent despite dismal prognosis,
- patients on ICU units with progressive multi-organ failure where ECMO therapy is being discussed,
- elderly patients with multiple comorbidities and repeatedly decompensating (but still recompensable) organ failure.

Especially in chronic disease and frail and comorbid conditions, when lifetime prognosis is felt to be compromised but more precise estimates are lacking, and when interventional therapies are still an option (hemodialysis, TAVI, MitraClip, ICU, ...), the term *palliative* might lead to confusion and denial: In clinical practice, it is inconsistent **what** the term *palliative* really means, which in turn affects the assessment of **when** palliative care should be offered to **which** patient, and **what** therapeutic interventions this should include.

In palliative and end of life care, these and numerous other terms can be found that might be understood in different ways by the patient, his/her relatives, doctors, nurses, and other health care professionals. What does, for instance, *final phase* of life really mean? When does it begin? What does *autonomy* mean? Can a patient fully maintain *autonomy* until the end of life, despite extensive supportive needs? And can a patient really lose his/her *dignity* when being excessively dependent on other persons and institutions, or isn't *dignity* an immanent concept of every human being that cannot be lost? Which interventions were meant when a patient wrote *"I refrain from any life-prolonging*

*treatment"* in his/her advance directive? Doubtlessly, communication between all persons involved in the care of severely affected patients would dramatically improve if the basis of communication, the terms in use, would be used more consistently. This might be especially true for the terms *palliative*, *curative* and *supportive*, where specialized teams, infrastructure and even disciplines have developed that need to be involved in an appropriate, differentiated manner.

### What is palliative? What is palliative care?

The World Health Organization (WHO) has initially defined palliative care as *"the active total care of patients whose disease is not responsive to curative treatment"* [1]. Despite its useful description of the conceptual contents that palliative care should deliver, it was not defined what *curative treatment* meant in this context – for instance, treatment interventions that are aimed at the complete, sustained absence of the disease (*cure*) or treatment interventions that aim to reduce disease manifestations, i.e. any cancer-specific therapies. If the latter understanding of *curative* would have been meant, palliative care would then have to be understood as a concept applicable to patients only if their causative therapies have been exhausted – this means, extremely late in the course of the disease. In 2002, the WHO definition was revised: *"Palliative care is an approach that improves the quality*

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**Key words:** Palliative, Palliative care, Supportive care, End-of-life, Curative, Nephrology

**Received:** July 11, 2018; **Accepted:** July 20, 2018; **Published:** July 23, 2018

of life of patients and their families facing the problems associated with life-threatening illness..." [2]. Obviously, the attempt was to overcome the (mis)understanding that palliative care was applicable only to patients in the very last days of their life. On the other hand, the term *life-threatening illness* can be interpreted to comprise any severe illness, regardless whether there is a context of incurability or not [3]. The European Association for Palliative Care (EAPC) used both interpretations in one and the same paper [4]: "*Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment.*" ... "*Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness...*". The EAPC even continues: "*Palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, ...*" and: "*Some aspects of palliative care may also be applicable to patients at risk of developing an illness and their families.*" This extremely broad understanding of what palliative care should potentially comprise, and the obvious contradictions in the above named statements, impedes proper and unambiguous communication, no matter whether "*not responsive to curative treatment*" is understood here as a situation where all disease-directed treatment is exhausted, or when *cure* is no longer an option.

### What is *curative*?

So, the understanding of the word *curative* has in turn enormous implications on the understanding of the term *palliative* and on the conception of palliative care services. An ASCO position paper [5] on palliative care in oncology might increase the confusion even further: "*Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.*" If *curative treatment* was understood here as any disease-directed (anti-cancer) treatment, it is certainly helpful that it has been clarified that (palliative) anti-cancer therapy is no contradiction to the implementation of palliative care. If *curative treatment* was meant as a treatment intended to cure the disease completely, then palliative care consequently would be applicable also in early, curable stages of cancer disease and in the adjuvant setting. The specific therapeutic (and ethical) circumstances of incurability would then fall away, and a broad overlap to (oncological) supportive care concepts would result (see below).

We therefore performed a survey, addressing international authors involved in palliative care definitions and guidelines in the context of oncology, and demonstrated that there is no common understanding of *curative* treatments (as a basis for their understanding of palliative care), especially when it came to differentiate between *curative* and *disease-modifying* therapies [6].

### What is "cure"?

From an oncology perspective, the confusion about terms like *palliative* and *curative* treatments is even more increasing, as often enough, it is unclear whether there can be a realistic hope for *cure* (in a sense of absence of disease for the rest of life). How many years of disease free survival (DFS) are demanded in order to define a *realistic* hope for being *cured*? Patients suffering from locally advanced head and neck cancer or locally advanced non-small cell lung cancer may be offered multimodal aggressive therapies in order to *cure* the disease, although the overall prognosis of these patients remains dismal (for instance, a 36% 5-year survival rate in stage IIIA NSCLC patients [7]). How bad must a prognosis be to *a priori* refrain from aggressive multimodal therapy and to pursue QoL-adjusted (*palliative*) systemic therapy instead?

This discussion is fuelled by new multimodal concepts for "oligometastasized" patients – patients demonstrating only few, resectable metastases where a survival benefit can be expected by aggressive multimodal therapy, as opposed to palliative systemic therapy [8]. But to denote this multimodal concept as *curative*, in an attempt to *cure* the patient completely, has to be questioned, though, with regard to the present, still dismal overall survival data, demanding for a *realistic* understanding of the term *cure*.

In the non-cancer setting, like in nephrology, this discussion might lead to even more amazement, as for most of diseases in internal medicine, there is no realistic hope for cure anyway (in a sense of absence of disease for the rest of life), making it even more necessary to clarify what "*not responsive to curative treatment*" means. From a palliative care perspective, it would be highly problematic if palliative care would be restricted to those situations where all *curative* (i.e. disease-directed) treatment would have been exhausted.

### What is "supportive"?

Also, the term *supportive* is used in several implications. Often, the term *supportive therapy* is reserved to all interventions used to relieve side effects of medical treatment and of complications of the disease. The term *supportive care* might be interpreted even broader, including contributions of social services or psychotherapy (psycho-oncology in the context of cancer). Jean Klastersky has recently outlined an even more comprehensive "umbrella" understanding of *supportive care* and has outlined the emerging confusion with the concept of *early palliative care* [9]. Interestingly, there is also a definition overlap in the WHO definition that describes palliative care as a *support system* [2].

The term *best supportive care* (BSC), though, is derived from clinical studies, and refers to a concept that is „neither well-defined nor standardized" [10]. Van Cutsem et al. defined BSC as "the best palliative care per investigator excluding antineoplastic agents", to make confusion in terminology even greater [11]. In a clinical trials scenario, the clarification of what BSC constitutes is of utmost importance also from methodological reasons, as previous years have provided enough evidence confirming the clinical and prognostic implications of structured, early-onset palliative care approach, thereby confounding study results within an undefined BSC arm. Nevertheless, in clinical day to day work, the term *best supportive care* is quite often used, and requires immanent clarification in order to avoid further communication problems.

When *supportive care* includes the treatment of the complications of the disease, there is an immanent overlap to the concept of *palliative care*, where pain and other symptoms and needs are understood as sequelae and complications of the disease (whereas treating complications of the disease also belongs to the self-conception of supportive care). This overlap becomes increasingly more relevant, as disease-directed therapies in all fields of medicine expand into the very late stages of the disease, due to the wealth of new therapeutic substances, and as palliative care intends to address patients earlier during the course of the disease, sometimes as early as from the time of diagnosis of an incurable disease.

In sum, the overlap between the terms *palliative* and *supportive* is multi-faceted. Pragmatically and consequently, the MD Anderson Cancer Center in Houston, Texas, performed a departmental name change from *palliative* to *supportive care*, in order to successfully implement *palliative care* earlier during the course of disease [12]. Also in Germany, the first *supportive care unit* has opened in Berlin [13].

## Conclusions

Even quite prominent terms in palliative and end of life care, like the terms *palliative*, *curative*, or *supportive*, bear numerous opportunities for mislead and failed communication. Current guidelines, definitions or position papers have not substantially contributed to clarification. Although it would highly desirable to have clearly defined terms, for instance with respect to departmental or structural offers, quality management, the reimbursement of efforts, or the quality of clinical studies, the most important aspect in patient care should not be lost out of sight: to thoroughly assess the patient's and the family's symptoms and needs, and to offer any comprehensive, therapeutic and supportive help the patient and the family requires – no matter how we name this kind of help and the according therapeutic institutions.

## Ethics approval

Not applicable

## Consent for publication

Not applicable

## Availability of data and materials

Not applicable

## Competing interests

The author declares that there are no competing interests

## Funding

None

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