

Pediatric Palliative Care: A Reflection on Terminology

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ABSTRACT: The definition of palliative care is the cornerstone of a medical subspecialty that plays a particular role for all who need it, for all who practice it, and increasingly for those who try to understand it.

The difficulties around the definition and terminology arise from problems in separating it from other concepts such as supportive care, constructs such as “palliative care is only about dying”, or, in children, the rather vague use of terms like life-threatening and life-limiting diseases. These weaknesses have been recognized and important steps have been taken. This review discusses current definitions as well as efforts to overcome their weaknesses and make the term palliative care—for both children and adults—more intelligible.

KEYWORDS: palliative care, children, definition of palliative care, understanding of palliative care

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Introduction

The introduction of palliative care often occurs late in the course of an illness that would require a palliative care approach, regardless of whether the patient is a child or an adult. Several reasons for this can be given; one of them is linked with the difficulty of understanding the definition and concept of palliative care, not only for laypeople but also for health care providers.

Thus, a recent article in the *Swiss Palliative Care Journal* was titled “Who in fact is palliative care?”¹ This article discusses 2 recent surveys of the general population in Switzerland.^{2,3} The first revealed that barely 50% of 1600 interviewees had ever heard the term “palliative care.” Those who knew about it held a generally positive opinion about palliative care services, and more than 90% thought that palliative care should be accessible for severely ill or dying people. The second study was aimed at analyzing people’s understanding of palliative care. What kinds of notions are related to palliative care in the general population and how are these understood? Seven such notions were predefined and presented

to a total of 50 people, who were interviewed face-to-face. These were:

1. Living to the end.
2. Palliative care allows the best possible quality of life to the last, despite severe illness.
3. Palliative care is counseling and not assisted dying.
4. Palliative care alleviates physical symptoms and also fears, uncertainties, and other suffering.
5. Palliative care means accepting dying.
6. Palliative care is help and support for people in their last phase of life.
7. With palliative care, a person receives holistic care and his/her autonomy is empowered.

The most favored notion was the second one, and those with the lowest support were the first and fifth. The second notion received the strongest support because it stirred up hope and a sense of emotional security. Mentioning “best possible quality of life” was deemed important, as



it also expresses that all are trying to do their best. Two aspects were suggested for change: “severe illness” should be changed to “incurable illness”, because severe illness does not necessarily lead to death; and “despite” should be changed to “because of” to remove the sense of antagonism. In general, the interviewees thought that palliative care should receive more publicity, which was a secondary aim of this survey.

This most recent survey with laypeople mirrors strikingly the ongoing knowledge gap and the relevance of formulating terms and definitions of palliative care comprehensibly. At least to some extent, it can be presumed that the knowledge gap among laypeople also reflects the ambiguity of terminology developed and used by health care providers—not only those working outside palliative care but also within the field. The aims of the following review were to discuss current definitions of palliative care, how they are understood and used, and the difficulties and impacts of shortcomings. The focus is on pediatric palliative care (PPC).

Vignette

A nine-year-old patient of mine suffering from incurable medulloblastoma read on my badge “Palliative Care” and pronounced “care” in German, that is, “Karre” (meaning barrow). I never thought of a wheelbarrow when talking about palliative care; however, I love this metaphor and have many images in my head about this wheelbarrow and what could be in it for children who still want to live and actually do so, irrespective of their closeness to dying and death.

The Definitions

In the 1970s, Balfour Mount in Canada developed the term palliative care⁴ and strove to professionalize the care of the dying within a general hospital. Palliative care has emerged from “care of the dying”, which finds particular reflection in the terms “hospice care”, “continuing care”, and “comfort care”, all of them used in an overlapping manner.⁵ The World Health Organization (WHO) adopted the term ‘palliative care’ and released the definition that is the basis of all further definitions used worldwide.⁶ Thus, in Europe, the following definition of the European Association of Palliative Care (EAPC) is predominantly used for adults:⁵

Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care—that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death.

It sets out to preserve the best possible quality of life until death.

For children, the definition of Together for Short Lives (TfSL, formerly ACT)⁷ is used:

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support.

Palliative care can be introduced at any point throughout a child’s life; it is completely individual. Some children may require palliative care from birth, others only as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments aimed to cure or significantly prolong life. In practice, palliative care should be offered from diagnosis of a life-limiting condition or recognition that curative treatment for a life-threatening condition is not an option; however, each situation is different and care should be tailored to the individual child.

What do current definitions avoid or gloss over?

A comprehensive and critical overview of the definition of palliative care was published by Pastrana et al.⁸ They analyzed the “self presentation” of palliative care in the specialized literature following the principles of discourse analysis, which has its roots in social science and linguistics.⁹ Four main categories with key elements of care were identified: (1) structure, including the multidisciplinary team approach and structure of service; (2) target groups in terms of patient population; (3) tasks of care, such as symptom control and also the concept of care; and (4) expertise with respect to specific knowledge, skills and attitudes of professionals. The central objectives of palliative care were found to be quality of life and relief of suffering. The authors criticize that the concepts of dignity and resilience are virtually lacking in these definitions and that the focus of palliative care seems to diverge from dying and death: “Our analysis showed that the relationship between palliative care and death and dying is strained and that these words were used even less in recent definitions. . . .” This has also been impressively outlined by Kellehear¹⁰ in his article on dying and human suffering: “We suffer not because we are in need but because we are in ‘mourning’ for what we have lost. [...] Actively addressing grief and distress of this kind, by the dying person or their carers, can extend life and shorten the emotional and social experience of dying as a form of suffering.” Therefore, the relationship to death matters also in the context of defining palliative care.



The Different Purposes of the Definitions

Cultural taboos connected with mentioning dying and death make definitions of palliative care difficult to formulate. Yet, a good definition provides a cornerstone for understanding and explaining its concept. Clear and unequivocal language is essential.^{5,11–13} Four purposes of a definition will be expanded upon below: (1) to distinguish it from other concepts, (2) to define patient populations, (3) to improve access to palliative care, and (4) to include dying and death issues.

Distinction from other concepts. Two EAPC White Papers have released norms and working definitions of palliative care.^{5,14} In these, it is clearly stated that the term “supportive care” should only be used in the context of oncology. The key elements of palliative care with equal impact in the care of a child and his or her family include quality of life, autonomy, relationship to healthcare professionals, and communication.⁵

Definition and terminology are mandatory for the definition of patient populations with a need for palliative care. The far-reaching problem of differing definitions and terminology, including implications for the definition of the palliative care population, has been recognized and is sufficiently documented.^{13,15–17} In pediatrics, 2 major advances in defining the population of children with palliative care needs have been made in the United States^{18,19} and England.^{16,20} This forms a key baseline for the particularities of PPC with respect to prevalence, needs for specialized PPC services (SPPCS), and further epidemiological and clinical research. Through these attempts, a definition of complex chronic conditions (CCCs)¹⁸ and a “Dictionary of Life-limiting Conditions”²⁰ have emerged.

Improvement of access to palliative care. In children, it has been shown that those who could have benefited from palliative care (and its definition) did not receive it, even if it was available.^{21–23} This limited access to SPPCS is documented in several studies.

In the United States, using the database of the Pediatric Health Information System, a retrospective cohort study analyzed the receipt of SPPCS in 24,342 hospitalized children (<18 years of age) who died ≥ 5 days after admission.²¹ Children who died within 5 days after admission were excluded, as the time needed to access PPC might have been too short. Only 919 (4%) of these children had a documented code for SPPCS. Infants accounted for 41% of deaths, but only 2% of them had received SPPCS. SPPCS receipt was more common in older children who died from diseases of the nervous system (9%) and malignancies (8%). Children with an SPPCS code received significantly fewer medications and fewer invasive interventions and were less likely to be admitted to an intensive care unit (ICU) or to die in ICU. In other words, only an extremely small proportion of hospitalized children who died (4%) had an SPPCS code, and the majority probably did not receive care that might have allowed better quality of life prior to death. According to the PPC guidelines enacted by the American Academy of Pediatrics in 2000,²⁴

the latter should no longer happen in children with palliative care needs.

Another study among 232 institutions of the Children’s Oncology Group in 2005 (response rate 81%), revealed the availability of SPPCS in 58% of the institutions; however, these were only employed in a minority of patients (in no children suffering a relapse).²²

In England, a study assessed the impact of SPPCS on the number of hospital admissions.²⁵ Of 2508 children (0–19 years of age) diagnosed with cancer between 1990 and 2009, 657 died, of whom 182 had received SPPCS and 475 had not. The groups differed in terms of age, with a smaller percentage of older ages and a higher percentage of CNS tumors in the SPPCS group. Patients referred to SPPCS had significantly lower planned admission numbers and rates compared with those who were not referred (10.0 vs 2.6 [$P < 0.001$] and incidence rate ratio, 0.60 [95% confidence interval, 0.43–0.85], respectively).

Besides these descriptive numerical data, which demonstrate that needs for SPPCS were not recognized in many children, outcome and impact of definitions may be evaluated by using a theoretical framework, as has been proposed by Bainbridge et al.²⁶ This framework is divided into system structure, process of care, and patient outcomes. A further attempt has been made by studying quality of life, one of the key elements of palliative care. “Does palliative care palliate?”²⁷ At least in adults, and predominantly in the field of oncology, efforts have been made to evaluate quality of life among different patient groups.^{28,29} Some first steps have also been taken in pediatrics,³⁰ with the result that existing instruments need to be adapted for this patient population. Therefore, on this level, it is too early to evaluate the impact of SPPCS on aspects of quality of life.

The role of death and dying in the definition. The underlying and well addressed concept of palliative care is the biopsychosocial model as defined by Engel.³¹ The biopsychosocial model encompasses all dimensions listed in the definitions and, even if not particularly exemplified, this also includes aspects of dignity and resilience found to be missing by Pastrana et al.⁸ However, dying and death seem to occur even less frequently in the more recent definitions.⁸ Supporting the analyses of Pastrana et al, I strongly support the idea that the definition of palliative care should connote a relationship to dying and death and thus include the clearly limited time of living—for adults as well as for children.

Views on Palliative Care

As outlined above, the term palliative care encompasses several difficulties, such as differing definitions, lay misunderstanding of the term, and also its understanding among health professionals from inside as well as outside the field. In the following paragraphs, I will focus on views, understanding, acceptance, and the position of palliative care within the general field of medicine.

Understanding by those who are in need of palliative care. “Listen. My child has a lot of living to do.” Many



will recognize this phrase not only reminiscent of an Elvis Presley song, but of literature on PPC, as the major wish of parents caring for a child suffering from life-limiting disease. The sentence illustrates that those who are deeply affected by incurable disease need help and do not want to be put on the end-of-life track.

In 2003, an impressive publication in *The Journal of the American Medical Association* had a subtitle that read, “Let me live the way I want to live, until I can’t.”³² This report on a 33-year-old African American man with advanced human immunodeficiency virus (HIV) infection, an excessively high virus load, and multiple comorbidities depicts the heterogeneity of challenges in the care of young adults suffering from AIDS. It also demonstrates the difficulty in narrowing down the concepts of curative and palliative treatment approaches and thus the necessity to overcome this obsolete dichotomy. The treatment of this young man highlights the rationale behind integrating curative or disease-modifying interventions, such as highly active antiretroviral therapy (HAART) and treatment of opportunistic infections with symptom alleviation. Further on, some of these patients may refuse to discuss advance directives, and it may be difficult to maintain a continuing and trustful relationship with these patients.

Understanding among professionals. As discussed by Selwyn,³² the false dichotomy of curative and palliative care often goes along with an exclusion of palliative care particularly in the context of oncology,^{33,34} where the main reason or barrier to palliative care is receiving chemotherapy. Further on, there is still an overemphasis on the curative model of medical care, as has been discussed in an editorial by Fox in 1997.³⁵ There, he elaborates on the theoretical construct of the curative model characterized by an inherent set of assumptions, attitudes, and values, for example, in a way of thinking that is primarily analytical and rationalistic or biomedically and organically focused, excluding soft values such as the individual values of the patient and his or her social context. Thus the curative model of medicine conflicts with the notion of a good death. Even if this may sound overstated for some, it is still a reality nowadays, even in pediatrics. Unfortunately, this also has an impact on medical education. Apart from that, there may be an overly simplistic view of the meaning of cure. As Kellehear discusses powerfully,¹⁰ people close to death (and even the family of a dying child) may look outside their suffering toward a source of healing. This “healing” is not meant in the sense of cure but of making sense, an essential part of the ongoing maintenance of a person’s or a family’s identity.

The position of palliative care within medicine. As long as the curative model and the palliative care model remain antithetical, there will not be a solution or even an approach to integration. Cure may not always be the primary and sole goal of care, but relief of suffering, autonomy, and quality of life certainly are. Accepting the limitations of medicine could humanize it in an important way. Therefore, there seems to be room for integrating the concept of palliative

care into medical thinking, particularly at this time of highly specialized medicine and attempts at further centralization.

How to Overcome the Difficulties of Definitions: A Look at the Particular Needs of Children

“It’s not that bad yet!” This frequently heard response to the suggestion of palliative care is, I believe, not only due to lack of acceptance but also to misunderstanding. Important steps toward clarification have been taken by the EAPC^{5,14} and through the definition of CCCs¹⁸ and the development of a dictionary of life-limiting conditions.²⁰ On the basis of these foundation stones, the definition of palliative care should become more workable and self-explanatory. A focus on children, I believe, would enhance acceptance and understanding of PPC. Thus, including aspects of the child’s needs may facilitate an understanding of PPC goals. PPC is not just a better concept of psychosocial care; its focus is on incurable disease with specific needs of care. The TfSL’s wording “active approach”⁷ probably refers to this. In parallel to a recently developed instrument that should help to identify children with PPC needs,³⁶ I would propose including some of these indicative aspects in the definition of PPC. The overarching criterion for PPC is a child of between birth and 18 years of age suffering from a life-limiting disease²⁰ or complex chronic condition, as defined by Feudtner et al,¹⁸ with disease progression, deterioration, or a significant degree of instability, which translates into 3 possible actions or scenarios:

- The first is a change of treatment goals with (a) a focus on quality of life (eg, a child with cardiac disease without further surgical options is looked after at home, with a team in the background that is ready to support the child and the family in case of crisis or when approaching the end of life) or (b) the introduction of experimental treatment without reasonable chance of success, such as experimental chemotherapy, experimental cardiac surgery, or life support with extracorporeal membrane oxygenation (ECMO)³⁷ in a desperate situation.
- The second is a change in daily activities, for example, a child with a previously nonprogressive neurological condition deteriorates due to recurrent pneumonia and, therefore, is no longer able to regularly attend school for disabled children but needs more professional care, support, and probably advance care planning. This means that the deterioration has a significant impact on the daily life of the child and the family. Only seldom will the child’s status change back to the earlier state of disease.
- The third concerns neonates, who constitute a particular patient group. They may fulfill criteria for a change of treatment goals (as in point 1 above); however, this must take place in an often very short time frame of hours or days and usually on the neonatal intensive care unit. Therefore, they should be regarded specifically.



These scenarios have a great deal in common with the 4 diagnostic groups as defined by TfSL.³⁸ To enhance the acceptance, understanding, and involvement of PPC, they should be presented together with easily accessible definitions of PPC.

The particularities of children. Children need specialized services that should be provided by pediatrically skilled staff. This applies especially to pediatric nurses and physicians. In addition, palliative home care for the support of children and their families should be available.¹⁴

The pivotal question of when to start palliative care cannot be answered within a brief sentence. It depends on several aspects and circumstances, and an instrument such as the Paediatric Palliative Screening Scale (PaPaS Scale) may prove helpful for professionals who are not familiar with PPC.³⁶ However, I disagree with the statement that it should begin at the moment of diagnosis of life-threatening diseases. This is too global and not a helpful directive, which may have led to greater confusion than clarity.

Conclusion

Palliative care is subject to widespread misunderstanding both outside and inside the medical profession. Clear definitions that are straightforward and courageous seem to fulfill the wish of a majority of laypeople to receive honest information not only when in need of help but also when looking for information on a delicate subject. One such definition is as follows: "Palliative care allows the best possible quality of life to the last in the case of incurable illness." This notion of palliative care, designed to educate the public, was valued most by laypeople surveyed in Switzerland. The concept of quality of life also emerged from an analysis of the "self presentation" of palliative care in the specialized literature. Interestingly, the preferred definition of laypeople did not exclude aspects of death in the context of palliative care. Thus, quality of life and relief from suffering as well as relationship to death are key components of palliative care definitions.

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Conceived the concept: EB. Wrote the first draft of the manuscript: EB. Made critical revisions: EB. The author reviewed and approved of the final manuscript.

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As a requirement of publication the author has provided signed confirmation of compliance with ethical and legal obligations including but not limited to compliance with ICMJE authorship and competing interests guidelines, that the article is neither under consideration for publication nor published elsewhere, of their compliance with legal and ethical guidelines concerning human and animal research participants (if applicable), and that permission has been obtained for reproduction of any copyrighted material. This article was subject to blind, independent, expert peer review. The reviewers reported no competing interests. Provenance: the author was invited to submit this paper.

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