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The need for a shared understanding: Domains of care and composition of team in pediatric palliative care guidelines

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Abstract: Conceptual confusion has been identified as one primary barrier to providing quality palliative care. This study aims to analyze pediatric palliative care guidelines from a conceptual perspective in order to facilitate a shared understanding of palliative care in pediatrics. Five online data bases were searched systematically, in addition to a Google search. Analysis focused on the language used to determine the domains of pediatric palliative care and on the composition of the pediatric palliative care team.

Guidelines express consensus on four core domains of pediatric palliative care: physical, psychological, social and spiritual care. However, further linguistic analysis revealed that conceptual vagueness exists with respect to the latter three as terminology is used inconsistently both within and across guidelines. It remains unclear what demarcates psychological care from emotional care, social care from psychosocial care, and spiritual care from religious or existential care. Furthermore, guidelines agree on the most prominent members of the pediatric palliative care team. Core domains of pediatric palliative care match these most prominent members of pediatric palliative care team. However, an inconsistent use of terminology affects the quality of pediatric palliative care in various ways. Therefore, a shared understanding and unambiguous language must be envisaged.

Keywords: Pediatric Palliative Care; Terminology; Guidelines; Core Domains; Team

Introduction

Pediatric palliative care (PPC) is a specialized medical model that seeks to care for pediatric patients, their families, and other significant persons using an interdisciplinary and holistic approach that focuses on several domains of care, such as psychological or spiritual care. Reduced child mortality rates and improved survival rates of pediatric patients with life-threatening diseases mean that there are more children who will need to access palliative care (PC), but only a fraction of these children actually receives and benefits from PC [1]. Several barriers to adequate implementation and sufficient provision of PPC have been identified in the literature, such as, organizational, cultural and economic obstacles [1]. Various scholars have also focused on the problem of conceptual confusion and in particular, on the lack of a shared understanding of PC [2-6]. They argue that good PC provision necessitates such a common understanding. Unfortunately, PC is often misunderstood both inside and outside the professional health care setting [4].

Recent studies in the US, Northern Ireland, the UK, Bangladesh, and Canada indicate that PC is relatively unknown among parts of the public and that persons who are aware of it often have a mistaken idea of its nature [7-11]. This knowledge gap may, at least partially, result from the ambiguous terminology used by health care providers [2]. Studies show that many physicians still equate PC with hospice care or end-of-life care [7], and even physicians and nurses who know the difference, associate PC primarily with death and dying [12]. Another study shows that practitioners are often uncertain about how to translate PC in practice [13]. These misconceptions and attitudes not only impact the lay understanding of PC, but also affect clinical practice in various ways, for example, whether and when patients are referred to PC. Hence, using the right terminology is important as it can influence both medical practice (e.g. reduce the number of late or non-referrals), and policy making (e.g. the allocation of more resources to PC as a result of awareness). The same vision is shared by the European Association for Palliative Care (EAPC): “it is obvious that an effective European approach to quality palliative care demands an unambiguous use of terms, which implies, as a prerequisite, the mutual agreement on the definitions of these terms" [3]. However, such a shared language requires a common standard of care to refer to [5]. With respect to PPC, this means that international guidelines that determine clinical practice need to be unequivocal. Knowing the concept of PC and being able to demarcate it from hospice or end-of-life care is not sufficient if practice guidelines remain vague and ambiguous.

Unlike the studies discussed above, this study's rationale is to explore the conceptual consistency within and across international PPC guidelines. The focus was set on PPC guidelines because of the increasing number of children with life-threatening diseases and consequently, the increase in children who need access to PC. Furthermore, the study concentrates, in particular on two main principles of PPC: holism (the various domains of PPC care) and multidisciplinarity (the composition of the PPC team). According to a conceptual analysis of PPC for pediatric nursing practice, holism and multidisciplinary are to defining attributes of PPC and therefore pediatric nurses' understanding of the concept of PPC enables them to continue improving and providing quality nursing care[14]. Consequently, our analysis covers two main research questions: (a) the functions, namely which domains of care are part of the palliative approach in the pediatric setting; and (b) the composition of the PPC team, namely which professions are part of it. In particular, this article will analyze the language used in PPC guidelines by focusing on the definitions of the PPC domains and on the PPC team composition in order to identify both conceptual consensus and possible conceptual inconsistencies. Implications of possible inconsistencies for clinical practice in general and PPC nursing in particular will be discussed. Since pediatric nurses often spend significantly more time providing care for the child and the family than other members of the PPC team, the impact of guidelines' conceptual confusion on clinical practice is of high relevance for them.

The purpose of this analysis is to advance the development of clear PPC language to result in a shared understanding and, eventually, improved practice.

Methods

Research design

A systematic literature search on both international and national guidelines on PPC was undertaken, resulting in 11 included documents. Subsequently, analysis of (a) the guidelines' language used to determine the core domains of PPC and (b) the composition of the PPC team was carried out, thereby addressing two PPC principles: multidisciplinarity and holism.

Inclusion criteria

The following inclusion criteria were used: documents have to be a) on PPC (infants, children, and adolescents are subsequently referred to collectively as "children"), b) developed by a national or international PC organization or a national agency, c) normative in the sense of providing standards regarding PPC, and d) written in English or German.

Exclusion criteria

Research articles on PPC guidelines were excluded and were analysed in a systematic literature review[15]. Further, guidelines dealing exclusively with one sub-aspect of PPC (e.g. spiritual care) and guidelines addressing the needs of only one sub-group of children (e.g. neonates) were excluded since the aim was to identify the core domains of PPC in general. Guidelines that focus exclusively on one sub-group of children or on one sub-aspect of care naturally do not touch on the question which set of domains constitutes PPC.

Search strategy

The literature search was comprised of two parts. First, employing the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework [16], five online databases (Scopus, PubMed, PsycInfo, Web of Science, and CINAHL) were scanned, combining search terms through Boolean algebra as follows: (Pediatric* or child* or adolescent*) AND (palliati* or palliative care or hospice care) AND (guidelines or recommendations). In order to identify further guidelines, a Google search was next performed using the above-mentioned search terms expanded by the inclusion of the term “guide” in the last parentheses: (guidelines or recommendations or guide). Scanning the five data bases resulted in 1206 documents, and the Google search in 27. Subsequently, 413 out of 1206 (databases) and 10 out of 27 (Google search) were identified as duplicates and removed; 810 documents remained (Figure 1).

During the next phase, two researchers screened all 810 titles and abstracts (or introductions, respectively), resulting in 22 documents that were potentially eligible. The references of the latter were checked for additional documents. Through this process 1 document was added. In a final step, the first author read the full text of the resulting of 23 documents. Evaluating these documents led to the exclusion of 12 documents because they (1) were not the latest version of a document, (2) focused mainly on adult PC and touched only superficially on PPC, (3) addressed only one sub-group of children, or (4) presented exclusively facts without suggestions on best practice. A final set of 11 guidelines published between 1998 and 2013 fulfilled the inclusion criteria (Table 1).

[Figure 1: Search process using PRISMA Systematic Review of Literature]

Analysis

The analysis was carried out in several steps (Figure 2). First, all domains and team members were extracted by reading one document at the time. The focus was set on how guidelines defined or outlined PPC, in particular which domains of care were considered constitutive for PPC, and on who was considered a member of the PPC team. Thereby, any domain of care that was used to define PPC was included in a list of all possible domains and any occupational group that was part of the PPC team was included in a list of all possible team members. Out of the eleven documents, 10 documents explicitly referred to domains of care that constitute PPC and eight to which occupational groups constitute the PPC team.

Second, those domains that were used in all documents to define PPC were identified as core domains. For example, psychological care was considered a core domain because all guidelines referred to it when defining PPC (Figure 3). Furthermore, all occupational groups were ranked according to how often they were considered a part of the PPC team by the guidelines (list in a descending order). This step resulted in four core domains of PPC, namely physical, psychological, social, and spiritual care, and a descending list of how often a specific occupational group was considered a member of the PPC team along with information on which documents referred to the respective occupational group.

Third, both authors re-read and examined the guidelines, focusing on the comparison of the guidelines' terminology with respect to the identified four core domains. This procedure allowed determination of both consensus and inconsistencies across and within guidelines. In particular, analysis of the guidelines' language used to designate domains of PPC employed the following categories of how two terms can interrelate: (a) distinction on different levels, (b) distinction on the same level, (c) used interchangeably, or (d) merged to one domain. The term "distinguished on different levels" refers to a subordination of one domain to another, for example emotional needs are often subordinated to psychological needs. The term "on the same level" points to two independent domains without one being subordinated to the other, for example psychological and physical needs are two independent core domains of PPC. "Interchangeably" means two terms are used as synonyms to designate the same domain of care, like for example social and psychosocial. A "merged domain" is characterized by two terms that are used jointly (at the same time), for example psychological-emotional care.

[Figure 2: Steps of analysis]

Results

In total, 11 documents were analyzed, 3 from internationally recognized organizations (one from the World Health Organization, two from the EAPC Taskforce for Palliative Care in Children), 8 from organizations working on a national level, spanning seven North-American or European countries (USA, UK, Canada, Ireland, Scotland, Germany, Austria).

[Table 1: List of included guidelines]

Core domains of palliative care

All documents, except for one that does not list particular domains of care [24], identify four core domains of PPC, namely physical, psychological, social and spiritual care. These domains are further discussed below and exemplified through quotes (Table 2).

[Figure 3: Core domains of PPC]

Besides these four core domains, other domains were used to define PPC. However, none of these secondary domains was used by all guidelines. Practical care, which refers to activities of daily living and home-based services, is considered a separate domain in three documents [18,23,26]. Other aspects of PPC, such as loss, grief, bereavement, end-of-life care [18], cultural care [25], or developmental care [18,20] are rarely considered separate domains of PPC.

Analysis of language revealed that conceptual vagueness exists especially with regard to the psychological, social, and spiritual dimension of care due to inconsistent terminology both within and across guidelines (Table 2).

[Table 2: Examples of conceptual vagueness]

Physical Care

Physical care is mostly identified with pain. Pain is used to indicate not only physical, but also psychosocial, spiritual [20], and emotional aspects of pain [17]. Frequently, the physical and emotional aspects of pain are grouped into broader categories of symptom management or pain management. Finally, one document uses the terms “clinical needs” and “physical needs” interchangeably when referring to children’s needs that require physical care [1].

Psychological Care

Across documents, the term “psychological care” is often used inconsistently because the concept is not sufficiently demarcated from emotional care (Table 2). First, some documents distinguish these two as different concepts. They either clearly distinguish psychological needs from emotional ones on the same level of definition [19], or they consider emotions to be a subcategory (different level of definition) of the broader psychological domain [1,20]. Second, one of the documents only uses the term emotional care and does not mention psychological care when referring to this particular need of a child [23]. Third, in one case the two terms are merged into a single domain of psychological-emotional care [25].

Conceptual inconsistency can be found not only across, but also within one and the same document. For example, two documents list emotional care as a PPC domain, thereby either implying that it covers psychological care or that psychological care is not a domain of PPC, but then clearly distinguish psychological from emotional support elsewhere, thereby apparently referring to different concepts [19,21]. Furthermore, one document lists both psychological well-being and the emotional impact of an illness as two separate subcategories of PPC’s domain of psychosocial care, thereby distinguishing emotional and psychological on the same level and subordinating both terms to psychosocial care [18]. Finally, in some cases both terms are used interchangeably [20,26], for example, one document first lists realms of a child’s suffering as follows: physical, psychological, practical, and spiritual, before it later enumerates “physical, (…), emotional, practical and spiritual needs of the child”, thereby apparently equating emotional and psychological needs across the two enumerations [26, p. 968].

Social Care

Social care is another concept that is used inconsistently both across, but especially within documents because it is not sufficiently demarcated from psychosocial care (Table 2). One document uses the terms “social care” and “psychosocial care” to indicate two separate domains by providing a separate section for each of them [18], thereby distinguishing them on the same level. Most guidelines, however, only use social care to designate this particular core domain of PPC [1,17-23,25,26]. In some cases, the term is coherently used throughout the text, hence avoiding conceptual vagueness [1,19,23], but in other documents it is used interchangeably with psychosocial care [17,20,21,25,26]. For example, one document first refers to the social domain (besides the psychological, spiritual and physical) that is addressed by PPC and later states that "psychosocial (…) domains of distress" or "psychosocial (…) needs" have to be addressed (besides physical, emotional, practical, and spiritual needs), thereby using both terms to describe the same domain and *a fortiori* equating both terms [26]. Another one uses the two terms interchangeably across two analogous enumerations of care domains (Table 2); the document uses "psychosocial" in the first enumeration, and the term "social" in the second[20].

Moreover, one document uses the psychosocial domain to define PC in general, but the social domain when defining PPC, therefore indicating that this represents a conceptual difference either between social and psychosocial or between PC for children (this particular PC includes the social domain) and adults (this particular PC includes psychosocial domain) [21].

Spiritual Care

The domain of spiritual care is frequently mentioned in connection with existential care (Table 2). One document distinguishes the two concepts on different levels by subordinating existential to spiritual care [18]. A few guidelines only use the term spiritual care, thereby avoiding conceptual vagueness [20,25]. Finally, one document lists spiritual care as a separate domain of PPC in the headings, but makes references to "spiritual/existential" or "existential or spiritual" care throughout the text [26], thereby creating one domain by merging both terms.

Other documents set spiritual care alongside religious care (Table 2). One document mentions a "family's religious background" (besides the cultural one) as an aspect of spiritual needs, thereby subordinating religious to spiritual care [1]. Furthermore, two documents differentiate spiritual and religious care on the same level, one as separate parts of an end-of-life plan [21], the other one requires formal caregivers to distinguish spiritual from religious practice [18]. Finally, in one document, both terms are merged to create one domain: for example, “access to spiritual and/or religious care” and “spiritual/religious worker” [19].

Composition of PPC Team

With the exception of three guidelines [20,23,24], all the other documents discuss the particular multiprofessional composition of the PPC team and insist on its interdisciplinary collaboration. The most frequently listed members are: physicians and nurses, followed by social workers, psychologists, chaplains, volunteers, and physiotherapists. A few documents also list occupational therapists, child-life therapists, spiritual advisors, and pharmacists as members of the PPC team (Table 3). All documents unanimously require the PPC team to collaborate with the family and the child.

[Table 3: Members of PPC team]

Some guidelines extend the PPC team to the following range of professionals or services: home health aides and a bereavement counselor [26]; a case manager and a rehabilitation professional [18]; a curative teacher [25]; a professional providing short break care, a teacher, a complementary therapist, and a hydro therapist [22]; and a speech therapist, a play therapist, a music therapist, and a dietician [21,22]. Finally, several documents highlight the importance of a designated person who coordinates the PPC services, such as a care coordinator [19,20,25], key worker [19], navigator [18], lead doctor and nurse [23]. However, no clear indications are given on how the various team members (how, when, under what circumstances, authorities, procedures etc.) can or should collaborate.

Discussion

In the analyzed documents, there is a broad consensus on the set of core domains (physical, psychological, social, and spiritual care) that constitute the holistic approach of PPC. However, across and even within some of the 11 documents, three of the four core domains lack conceptual clarity (except physical care), as the use of the terms is often inconsistent. Because an effective approach to quality PC necessitates an agreement on definitions of terms, it is paramount to examine how this conceptual confusion might affect the quality of PPC. Therefore, in the following, this conceptual confusion and its impact on clinical practice will be addressed which is particularly relevant for pediatric nurses who, given their multiple skills and responsibilities, are involved in the provision of all four core domains of care.

PPC core domains

First, it remains unclear what separates psychological care from emotional care, social care from psychosocial care, and spiritual care from religious or existential care. Whereas the term "psychological" embraces both cognitive and emotional aspects, the term "emotional" refers to affective states (e.g. pleasant, unpleasant) and thus has a narrower focus than psychological care [27,28]. An enhanced and broadened focus would better respect a child's human right to development (enshrined in article 6 of the United Nations Convention on the Rights of the Child) which, among other factors, requires support for intellectual development [29,30]. For the PPC context, intellectual needs are cognitive aspects of care, such as those related to a child's growth in knowledge, critical thinking, learning new things, or making sense of her or his illness experience. These aspects reach beyond mere schooling and education, which represent rather formalized areas of children's intellectual development, and need to be made available. Apart from neglecting the cognitive needs of children, an overly narrow focus on emotional needs might reinforce the assumption that children, due to their age and developmental stage, are cognitively impaired, lack decisional capacity, and therefore, need surrogate decision-makers. This reinforcement decreases the likelihood of children's involvement in the decision-making process, for example, on whether to start PC. Including children in these decisions is unanimously recommended by all analyzed guidelines, as well as by the United Nations

Convention on the Rights of the Child [30]. Therefore, the term psychological is preferable to emotional care as it encourages health care providers to involve children in the decision-making process, simultaneously identifying and meeting both cognitive and emotional needs.

Furthermore, not sufficiently demarcating social from psychosocial care leaves the question open of how these types of care are different. Unlike “social,” the term “psychosocial” pertains to the interwoven psychological and social aspects of care as well as to the social determinants of health [31]. In contrast, social care more narrowly focuses on the social relations and significant others themselves (e.g. family, friends). However, social relations sui generis have a direct impact on the psychological state of the individual, and therefore, the psychological dimension is always implicitly considered by social care. That being said, one can legitimately raise the question what the term “psychosocial care” actually adds to social care? Ultimately, the term “psychosocial” more directly refers to the twofold meaning of social relations, namely the relations themselves and their impact on the person’s psychological state. Given this blurred demarcation, it is unsurprising that studies have shown that the provision of psychosocial care is hampered due to unclear areas of responsibilities among team members [32]. Especially with respect to psychosocial care, it is therefore important to not just assume and articulate that team members work together effectively, but to critically examine the collaboration [32].

Finally, spiritual care lacks conceptual clarity as it is narrowly connected with existential or religious care, but the relations among these three terms remains blurry. Given the subordination of existential and religious care to spiritual care in the guidelines, spiritual care appears to be the most suitable term in order to designate this particular core domain of PPC. This is further backed up by experts’ understanding of spirituality as composed of various elements, such as religious and existential aspects [33]. Using spiritual care as the most inclusive term might also align with modern pluralistic societies and suggests a neutral, inclusive stance of medical guidelines.

Second, diverging definitions of psychological, spiritual, and social care might hinder an adequate understanding of the core domains of PPC, and this may influence the creation and coordination of an effective PPC team to provide best possible care. The members of the team can only reach an agreement on how to operate if they have a clear understanding of their individual roles and responsibilities. Misunderstandings about each other's tasks, skills and expertise might cause interpersonal conflicts and competition [34]. For example, a study has shown that with respect to psychosocial care, PC team members exhibit a lack of clear role boundaries. Some members believe that any team member can meet the patient's psychosocial needs [32]. Interestingly, nonspecialist psychosocial team members perceived these unclear roles and responsibilities as positive, specialist psychosocial team members as negative. According to O'Connor and Fischer, this situation causes a division of the team because it leads to so-called "contested realms", that is, team members attribute specialist expertise to themselves while doubting the expertise of their colleagues [32]. Due to their nature as multiskilled professionals, pediatric nurses are especially prone to facing overlapping roles and responsibilities when working in a multidisciplinary team. Again, a shared understanding of language that avoids ambiguous terms and a clear understanding of individual roles facilitate skillful communication within the team. Members of the team, and nurses in particular, need to be able to articulate their expertise and knowledge in order to maximize the benefit from the numerous skills of the PPC team members[34]. Literature also shows that reflective practice among team members, for example hearing narratives of experiences by other team members, can serve as an additional measure to improve teamwork and future success [35]. However, in order to enable an improved practice in such a way, it is necessary that the team members share the same terminology and use it consistently.

In an efficient team that works successfully towards its goals, every member needs to have a clear understanding of their own contribution to the team [36]. Besides interpersonal conflicts and competition, differing uses of terms among team members can result in partially conflicting or overlapping understandings of one owns contribution, and thereby in different types of care, in involving different experts, and possibly in not meeting a child's needs sufficiently. For example, the term psychosocial care indicates the need to focus on the impact that social relations have on the child's psychological state, for example through psychotherapy or psychiatric drugs. Social care, on the other hand, puts more emphasis on the social relations themselves that can be addressed by a social worker through involving significant others within a systems approach. Even though psychological care refers to both a child's intellectual needs, for example explaining the cause of the disease in a developmentally appropriate way to the child, and emotional needs, for example dealing with a child's despair with the help of a psychooncologist, the guidelines sometimes represent only the emotional component and neglect the intellectual. Finally, if spiritual care is limited to providing religious care, a hospital chaplain might be the best choice, but if it rather embraces existential care, an occupational therapist, which helps to make hand prints for reminiscence is better meeting the requirements. As apparent from the preceding examples, the particular understanding of one domain of care determines not only which occupational group is involved, but also the factual care outcome.

Composition of team

First, all analyzed documents emphasize that PPC should be put into practice by a multiprofessional team whose work is not limited to the hospital setting, but that works across several health care settings and adapts care dependent on a child's particular needs. The team members should collaborate in an interdisciplinary way.

Results of the analysis revealed that the core of the hospital's PPC team is comprised of a physician and a nurse. Social workers represent the second most-mentioned group and psychologists, clergy, and volunteers the third. Other staff members, like for example occupational therapists and pharmacists, are listed only occasionally. The results confirm some important findings of other studies that show that for PC experts the core team is composed by physicians and nurses (absolute minimum), psychologists, social workers, and physiotherapists [37]. However, in the same study some controversies were found regarding the relevance of psychologists' and chaplains' contributions which are somehow mirrored by the fact that some of the analyzed documents do not list these groups.

Second, the question of how the team members' interdisciplinary collaboration should look like was not addressed substantially, as this best practice advice was only mentioned but not elaborated in depth. This is unfortunate, since, according to Remke and Schermer, a shared vision of how the team's objectives will be achieved promotes successful team work by increasing the degree of efficiency, of trusting one another, and of satisfaction with the own role [38]. Besides, it is vital for nurses working in the field of PPC to not only know the members of the PPC team, but to be provided with fundamental information on the interdisciplinary care approach[14].

The disagreements regarding the final team composition (beyond physicians and nurses) and the unspecified interdisciplinary collaboration represent a double-edged sword. On the one hand, this unfixed model takes account of the necessity of a flexible, highly individual-based, and context-sensitive approach of PPC by preserving open-endedness and adaptability of care [39]. On the other hand, this unfixed model opens the doors to interpersonal conflicts in light of team members' tendency to protect their own expertise in case of overlapping skills [34].

Third, most guidelines agreed on designating a coordinating person that serves as both a port of call for the family and, at the same time, as a centre of convergence for important care-related issues. Recent studies emphasize that coordination of a multiprofessional teamwork is crucial for providing quality PC and reaches beyond only one single coordinating person, for example to multidisciplinary team meetings or team training programs [32,36]. However, one designated coordinating person seems to conform to a minimum of coordination which has to be at hand in every team at every moment. A coordinating person should address the task of monitoring the team's composition and collaboration, thereby helping to avoid interpersonal conflicts among team members and unmet needs of the child. Because pediatric nurses are key members of the PPC team who provide multiple domains of care and spend significant amounts of time with the child and the family, they represent a suitable candidate for coordinating care that is in the best interest of the child. In fact, empirical evidence shows that referral rates were greater in PPC teams with an advanced nurse practitioner [40].

Fourth, the two analyses (domains and team composition) converge because the four identified core domains of PPC can be covered by those occupational groups which are considered members of a PPC team by the majority of the guidelines. That is, physicians, nurses, social workers, psychologists, and chaplains are capable of providing the physical, psychological, social and spiritual domains of PPC. Thus, the matching domains and occupational groups represent a major consensus across the PPC guidelines.

Limitations

First, exclusively guidelines that were written in English or German were included. Guidelines written in other languages may have revealed other or additional findings. Second, guidelines relevant to this study might have been overlooked because of the search terms that were chosen for the literature search. Third, to some extent linguistic differences reflect cultural and historical differences. Such differences may have an impact on the concrete form of PC and on the used terminology. Consequently, differences in terminology (due to cultural and historical differences) will continue to exist and are legitimate, but this study's findings rather reflect differences that resulted from an overall conceptual confusion and a not sufficiently attentive use of terminology.

Conclusion

Our analysis indicates a broad consensus on four core domains in PPC guidelines: physical, psychological, social, and spiritual care. At the same time it reveals a lack of conceptual clarity for the latter three. This is problematic insofar as conceptual clarity is an important prerequisite for quality PPC. Consequently, these terms need clarification, whereby the avoidance of using multiple terms for designating the same domain (e.g. psychological and emotional) can serve as a first step. The terms should be used more deliberately, considering (seemingly) small linguistic differences and their (likely) effects on the clinical context. Since nurses are involved in all core domains of PPC, an unambiguous terminology that facilitates quality PPC is especially beneficial for pediatric nurses. Despite the beneficial results of shared terminology, the authors acknowledge that several barriers complicate a consensus. With respect to terms and definitions, countries differ considerably regarding their history and language. Similarly, a delphi-study on common understandings of PC, highlights the different historical developments of PC among European countries as potentially hindering [37], and considers the specific nature of PC as set out by the WHO to be a barrier to reaching an agreement regarding the scope of PC. Still, any adequate PC definition should be based on patient needs and on the corresponding domains of care.

Apart from affecting medical practice, conceptual vagueness might magnify the already existing knowledge gap of PC among the lay public. This pathway is mediated by the inconsistent use of terminology among professionals. Inconsistent guidelines lead to an inconsistent use of terminology among health care professionals which eventually contributes to laypeople’s knowledge gap and confusion; Bergstraesser has rightly stressed this interplay [2]. It is self-evident that greater knowledge, less confusion, and raised awareness for PPC on the part of the lay public (but also within academia and clinical practice) promotes higher acceptance and consequently, in the long run, more resources allocated to PC.

With respect to a PPC team's composition, PPC guidelines agree on a standard that contains physicians and nurses, and that is complemented by several other professions. The guidelines neither specify how these occupational groups should collaborate nor who is ultimately part of the complementary group. This situation comes along with benefits and risks. It is of crucial importance to work toward further improvement, for example by designating a coordinator who utilizes this ambiguity to tailor palliative care to the child's specific needs.

Although the analysis focused on PPC guidelines and some of the findings are specific for PPC (e.g. reinforcing the notion of children's lack of decisional capacity by neglecting their intellectual needs which, in the end, decreases the likelihood of their involvement) other findings (e.g. the importance of consistent terminology in order to provide adequate PC) can also be valid for adult PC and reach beyond the pediatric setting.

Finally, the authors acknowledge that PPC, under all circumstances, must be an individually tailored endeavor that cannot be fully formalized. Aiming for a shared understanding of PC domains in order to facilitate optimal care does not contradict this notion. On the contrary, high quality care requires pre-existing structures and expertise on which the team can build the best possible care, thereby meeting the individual's needs through adapting to the child's particular illness profile [6]. This study contends that the underlying structure, expertise, and quality of care can be facilitated by a consistent use of language, as expressed by R.W. Emerson: "thought is the bud, language is the blossom, and action the fruit behind it".

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