

*Special Article*

## International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS

Franca Benini, MD, Danai Pappadatou, PhD, Mercedes Bernad , MD, Finella Craig, MD, Lucia De Zen, MD, PhD, Julia Downing, PhD, Ross Drake, MD, Stefan Freidrichsdorf, MD, FAAP, Daniel Garros, MD, Luca Giacomelli, PhD, Ana Lacerda, MD, Pierina Lazzarin, BSc, Sara Marceglio, PhD, Joan Marston, RN, Mary Ann Muckaden, MD, Simonetta Papa, PhD, Elvira Parravicini, MD, Federico Pellegatta, RN, and Joanne Wolfe, MD

*Paediatric Palliative Care, Pain Service, Department of Women's and Children's Health, University of Padua, Padua, Italy; Professor of Clinical Psychology, Department of Mental Health and Behavioral Studies, Faculty of Nursing, National and Kapodistrian University of Athens, Greece; Associated Professor of Pediatrics, School of Medicine, Universidad de la Rep blica, Pereira Rossell Hospital Center, Pediatric Palliative Care Team Director, Montevideo, Uruguay; Consultant in Paediatric Palliative Medicine at the Louis Dundas Centre, Great Ormond Street Hospital for Children, London, UK; Pediatric Palliative Care and Pain Service, Institute for Maternal and Child Health Burlo Garofolo, Trieste, Italy; International Children's Palliative Care Network (ICPCN), Uganda/UK; Pediatric Palliative Care and Pain Services, Starship Children's Health, Auckland District Health Board, Auckland, New Zealand; Professor in Pediatrics, Medical Director, Center of Pediatric Pain, Palliative and Integrative Medicine at UCSF Benioff Children's Hospitals in Oakland and San Francisco, California, USA; Department of Pediatrics, Division of Critical Care, University of Alberta, Edmonton, Alberta, Canada; Stollery Children's Hospital PICU, Edmonton, Alberta, Canada; Polistudium srl, Milan, Italy; Department of Pediatrics, Portuguese Institute of Oncology, Lisbon Centre, Lisbon, Portugal; Department of Engineering and Architecture, University of Trieste, Trieste, Italy; Sunflower Children's Hospice, Bloemfontein, South Africa; Tata Memorial Hospital Mumbai, Maharashtra, India; Columbia University Medical Centre, USA; Paediatric Hospice, VIDAS Association, Milan, Italy; Department of Psychosocial Oncology, Dana-Farber Cancer Institute and Department of Pediatrics, Boston Children's Hospital, Boston, MA, USA*

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### Abstract

**Context.** Since the publication of the IMPaCCT project in 2007, much effort has been made to develop new approaches to pediatric palliative care (PPC). Fifteen years later, it is time to redefine the standards in PPC.

**Objectives.** An international group of experts in PPC has revised the standards in PPC through the GO-PPaCS project (Global Overview – PPC Standards). The goal was to update the PPC standards considering the specificity of different settings, resources, and emerging challenges. The present document is intended to reach all people directly or indirectly involved in PPC.

**Methods.** A literature review in MEDLINE was conducted to expand on the fundamental points and current standards on PPC and to cover an international setting. The literature search (updated on the 15th of April 2021) was carried out using different combinations of keywords and focusing on papers published in English over the past 5 years (2016–2020), but older articles were considered when relevant. The consensus on the fundamental points, standards of care and paper contents was reached by open discussion.

**Results.** Fundamental points were defined regarding the definition of PPC, eligibility criteria and the magnitude of the need for PPC, while standards were redefined for the following six areas: 1) clinical, developmental, psychological, social, ethical and spiritual needs; 2) end-of-life care; 3) care models and settings of care; 4) PPC in humanitarian emergencies; 5) care tools; and 6) education and training for healthcare providers.

**Conclusion.** The present document, developed with the contribution of an international group of experts from different countries, experiences and models of care, provides fundamental points and standards for a wider implementation of PPC

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*Address correspondence to:* Franca Benini, MD, Paediatric Palliative Care, Pain Service, Department of Women's and Children's Health, University of Padua, Padua, Italy. E-mail: [franca.benini@aopd.veneto.it](mailto:franca.benini@aopd.veneto.it)

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### Key Words

*Pediatric palliative care, international standards for pediatric palliative care, life-limiting conditions, life-threatening conditions, terminal illness*

### Key Message

An international group of experts in PPC has revised the standards of PPC through the GO-PPaCS project (Global Overview – Pediatric Palliative Care Standards). This article provides this update, considering the diversity of settings and resources, and the emerging challenges in PPC.

### Introduction

In March 2006, a group of international experts in pediatric palliative care (PPC) assembled in Trento, Italy, under the auspices of the IMPaCCT (International Meeting for Palliative Care in Children, Trento) project, supported by the “No Pain For Children” association. They aimed to define the core standards for PPC in Europe.<sup>1</sup> At the time, that was the first regional attempt to develop a more uniform definition of standards and procedures in PPC. During the IMPaCCT, PPC was defined, best practices of PPC and different models of PPC service were identified, and minimum standards were shared. The outcome was “*a united document for Europe, defining and identifying standards of care for children with life-limiting and terminal illness.*”<sup>1</sup> The previously published standards aimed to inform and promote the implementation of improved and uniform management of PPC services across Europe, through the application of a set of defined core standards.

It has been 15 years since the publication of the outcomes of the IMPaCCT project. The WHO now identifies PPC as an ethical responsibility for all healthcare systems.<sup>2</sup> The number of children needing PPC has increased, mainly due to their longer life expectancy and the broader eligibility criteria now applied. In addition, new models of PPC delivery have been developed over the past 15 years, which were not covered by the previously defined standards of care.<sup>3–5</sup> This increase in the number of patients, PPC services and settings has been paralleled by an increased number of research publications that have become available. According to a PubMed search, using the keywords “pediatric palliative care,” 106 papers were published in 2006, compared with 827 in 2020. This adds complexity and requires a thorough reviewing of the existing standards to adapt them to the emerging needs, expanding knowledge and experience. Furthermore,

IMPaCCT was focused on the experience of European countries, while more universal standards are now required to address the needs of countries with limited resources.<sup>6,7</sup> Other pivotal documents on the general principles of palliative care and PPC have been published, but they were either focused on palliative care *per se*, and not specifically on PPC, or referred to specific countries.<sup>8–12</sup>

A recent meta-analysis of 24 studies clearly pointed out that children receiving specialized PPC have a better quality of life (QoL) with benefits for their families and the healthcare system.<sup>13–15</sup> However, some barriers persist and prevent a standardized approach to PPC both in high-income countries and in settings with limited resources.<sup>3–5,13,16–18</sup> For instance, access to essential analgesic drugs (e.g., opioids) is still limited in many countries.<sup>2,19</sup> Other barriers include gaps in applied standards, both across different regions of the world and within the same country, scant or poorly allocated financial resources, limited development of new therapeutic strategies and care models, nonspecific educational curricula for the training of healthcare providers and students. Due to all these barriers, it is not surprising that existing PPC standards are not widely applied in clinical practice, especially concerning the maintenance of good QoL throughout the entire life trajectory.<sup>19</sup> Therefore, there is an urgent need for a critical revision and update of current recommendations and practices to promote a wider implementation of PPC standards in all countries and different settings.<sup>13,18,20,21</sup>

An international group of experts in PPC has undertaken the task to revise the IMPaCCT standards through the GO-PPaCS project (Global Overview – PPC Standards). This project does not minimize the value of the IMPaCCT standards<sup>1</sup> but rather seeks to complement the efforts made by the pioneers in PPC 15 years ago according to current evidence and ongoing discussion in PPC. The goal is to redefine and update the PPC fundamental points and standards, by taking into account the specificity of different settings, resources, and emerging challenges.

In this paper, we present the methodology, the definitions of PPC, a revision of the magnitude of the needs and all the standards that emerged from the discussion among Authors. Further explanation on the standards is reported as appendixes. This document is

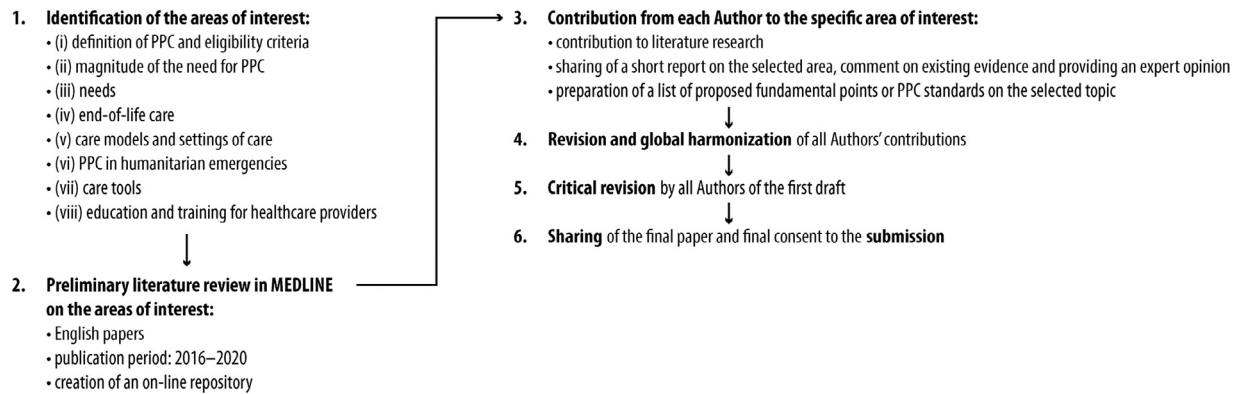


Fig. 1. Flow diagram of the review process and paper preparation.

intended to reach those directly or indirectly involved in PPC, including – but not limited to – healthcare providers, volunteers, educators, policymakers, and stakeholders. The proposed standards refer to an optimal response to the child and family needs, which is the goal of holistic care. However, this response should be adapted to the available resources and possibilities of each locality and/or country. Families can also benefit from this document to better identify their rights and address their needs in collaboration with the PPC team. Furthermore, educators can also be helped in the development of curricula for different audiences and levels of PPC training. Finally, policymakers can be guided in the regulation, development, and evaluation of PPC services, especially in countries that seek to integrate PPC into their healthcare system.

## Methodology

The Authors decided to critically revise and update the recommendations and statements presented in the IMPAACT project<sup>1</sup> by reviewing the most relevant advances in PPC since 2007 and expanding the standards to cover a more international setting. To that end, they sought the assistance of an independent scientific consultancy agency (Polistudium srl, Milan, Italy) in order to assist with scientific accuracy, planning, coordination of meetings and provision of materials. The project was christened GO-PPaCS and was supported by an unconditional grant from Fondazione Maruzza (Rome, Italy).

The Authors aimed to generate an overview document that covers all the areas of application of PPC. Following extensive discussion, it was decided that the present article should comprise a qualitative review that includes selected articles, associated with changes and novel developments in the application of the standards of PPC.

Therefore, the GO-PPaCS project was developed using a structured methodology that had already been used in similar cases with a broad range of topics

identified among Experts.<sup>22,23</sup> A flowchart of the project is displayed in Fig. 1. All decisions were reached by consensus during several online and in-person meetings.

According to a preliminary literature search on recent evidence and developments in PPC, the following eight areas were identified by consensus among the Authors to be included in the literature review: 1) the definition of PPC and eligibility criteria; 2) the magnitude of the need for PPC; 3) clinical, developmental, psychological, social, ethical and spiritual needs; 4) end-of-life care; 5) care models and settings of care; 6) PPC in humanitarian emergencies; 7) care tools; and 8) education and training for healthcare providers. The first two areas were considered as “fundamental points” while “standards” were defined for the other six areas. The Authors decided not to focus on the cost-effectiveness of different models due to their high variability across different countries.

A preliminary literature review in MEDLINE was conducted on each of the above-mentioned areas, using different combinations of pertinent keywords (e. g., PPC AND epidemiology, PPC AND patient need PPC AND education) and focusing on papers published in English over the past 5 years (2016–2020). The results and the retrieved papers were made available to all Authors via a designated online database. The literature search was updated on 15 April 2021.

Each Author was then asked to 1) select a specific area that was relevant to their personal experience and research interests; 2) contribute to the literature search, without any inclusion/exclusion criteria, according to their judgment and proposing other papers from their personal collection of literature or other sources/databases; 3) share a short report on the assigned area, comment on existing evidence and providing an expert opinion; 4) provide a list of fundamental points or standards. All contributions were then combined into a preliminary draft, after revision and global harmonization. Standards for each of the six areas mentioned above were defined in the ‘Standards’

section and commented in that section or the appendices.

The manuscript draft was then shared among all Authors, who are representative of all continents and different care models. They were offered the opportunity to critically revise the manuscript, add further references, evaluate the applicability of the proposed content in their own settings of practice, and add any comments. Fundamental points and standards were discussed, and disagreement was resolved by consensus.

The Authors then discussed the manuscript and associated comments during online meetings. A final version of the manuscript was subsequently circulated again to all Authors for the final consent to the submission.

## Fundamental Points

### *The Definition of PPC and Eligibility Criteria*

#### Fundamental Points

- PPC is a right for all children with a life-threatening or life-limiting illness and their families
- All children with a life-limiting, life-threatening or terminal disease are eligible for PPC
- PPC should improve QoL and address the needs, choices and wishes of children and their families
- PPC should not be limited to end-of-life care but introduced at the time of the diagnosis of a life-limiting or life-threatening condition, or in some instances prior to diagnosis when it may become challenging for example, cost of tests, a rare condition, advanced disease
- The level of care provided should be defined according to the specific needs of the child and family and may change over time
- There are distinct levels of palliative care (palliative approach by all healthcare providers, generalized PPC, specialized PPC), which should be offered by professionals with appropriate levels of training in PPC
- All definitions are general and should represent the ultimate goal of practice in PPC. Local conditions and resources should be taken into account

The WHO defines palliative care as ‘*an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.*’<sup>2,24</sup> This requires ‘*a broad multidisciplinary approach that includes the family and makes*

Table 1

#### Classification of Conditions Where the Child May Need PPC

Category	Description
Life-threatening condition	A condition with a high probability of premature death due to severe illness, but also a chance of long-term survival to adulthood for example: children receiving cancer treatment, children with severe neurological impairment, children in intensive care due to acute injury, children with technology dependency
Life-limiting condition	A condition where there is no reasonable hope of cure: premature death is expected, for example: Duchenne muscular dystrophy, Tay Sachs Disease, Trisomy 13, Trisomy 18
Terminal illness	A condition in which death becomes inevitable in children with life-limiting or life-threatening illnesses

use of available community resources; it can be successfully implemented even if resources are limited’. With more specific reference to PPC, WHO states that ‘*Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.*’<sup>25</sup> PPC is introduced when the illness is diagnosed and should be continued regardless of whether a child receives treatment for their disease. Importantly, PPC should not be restricted only to the end-of-life period. These definitions can be considered valid today, and access to PPC is recognized as a right for children and their families (please note that when we refer to ‘parents’, we intend ‘parents and legal guardians’).

Conditions for which the child may need PPC can be classified as life-threatening, life-limiting (both also refer to serious illness), or terminal (see Table 1).

According to the expected disease trajectory, medical conditions of eligibility for PPC have been classified into five categories (Table 2).<sup>1,12</sup> The fifth category involves unborn children with major health problems who may not live through birth, infants who may survive for only a few hours/days, infants with birth anomalies that may threaten vital functions, and infants for whom intensive care has been appropriately applied but developed an incurable disease (Table 2).<sup>18,26–30</sup>

For these infants and their families, perinatal palliative care (PnPc) may be the only option available.<sup>31,32</sup> Advancements in diagnostics during pregnancy and medical technology have changed the landscape of perinatal care, and the palliative care approach is now introduced in obstetrics and neonatal care.<sup>26,27,33</sup>

An alternative, more clinically-oriented classification comprises children with oncological, non-oncological and “with no specific diagnosis” disease (i.e., when a diagnosis has not been reached).<sup>33</sup> However, the diagnosis alone should not represent the only eligibility criteria for PPC, but the complexity of each child’s and family’s needs should always be taken into account.<sup>31,33,34</sup> In addition, complex chronic



Table 2

**Five Categories of Life-Limiting and Life-Threatening Conditions [Together for Short Lives 2018]**

Group	Description
1	Life-threatening conditions for which curative treatment is possible but may fail. Access to palliative care services may be necessary due to the complexity of the patients' needs (e.g.: cancer, complex congenital cardiopathies, severe injuries resulting from trauma) There is no longer need for palliative care services upon achievement of long-term remission or following successful curative treatment
2	Conditions in which premature death is inevitable; however, long periods of intensive treatment aimed at prolonging life and allowing for a good QoL (e.g.: cystic fibrosis)
3	Progressive conditions without curative treatment options, for which treatment is exclusively palliative and may commonly extend over many years (e.g.: Batten disease, muscular dystrophy, chromosomopathies)
4	Irreversible but non-progressive conditions with complex healthcare needs leading to complications and, likely, premature death (e.g.: severe cerebral palsy and disabilities following brain or spinal cord injury) Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.
5	Unborn children with major health problems who may not live through birth, infants who may survive for only a few hours/days, infants with birth anomalies that may threaten vital functions, and infants for whom intensive care has been appropriately applied but developed an incurable disease

conditions have to be considered and are defined as *'Any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center'*.<sup>35</sup>

It is of utmost importance that eligibility criteria become standardized.<sup>33</sup> Some "red flags" suggesting the need for PPC have been proposed (Table 3).<sup>33,36</sup> PPC should be provided when any of these eligibility criteria are met.<sup>37</sup>

Because of the specific characteristics of each disease and the anatomical and physiological features of

children, adolescents and their families should be integrated into well-structured, specific care programs taking into consideration the available resources and possibilities of assistance by qualified healthcare providers from different disciplines immediately after the diagnosis,<sup>13,33,36</sup> or before diagnosis, if needed. Such programs may deliver palliative care services at one of the following three levels: 1) *palliative approach* by all healthcare providers, 2) *generalized PPC* (i.e., provided by specialists of a given disease with training in PPC), or 3) *specialized PPC* (i.e., provided in a dedicated setting by an interdisciplinary team of experts in PPC) (Table 4).<sup>38–40</sup> Noteworthy, patients and their families can move between the three levels of care depending on the changes in their physical and psychosocial status. While the definitions provided above must adapt to PPC services worldwide, approaches to care should be tailored to diverse healthcare systems, specific training of healthcare providers, and available resources.

*The Magnitude of the Need for PPC***Fundamental Points**

- It is necessary to define the approaches used to collect data on the epidemiology of PPC
- Healthcare providers and policymakers should design care models and allocate resources according to the number and needs of children and families eligible for PPC

It is widely accepted that more than 20 million children worldwide are eligible for PPC, with a prevalence ranging from 120/10,000 children in Zimbabwe to 20/10,000 or 63.2/10,000 (according to different estimations) in the UK.<sup>6,41</sup> The prevalence of life-limiting conditions is highest in children aged <1 year and among those living in deprived areas.<sup>2,41</sup>

The number of children eligible for PPC is increasing worldwide. Earlier data on estimates showed that at least 10 out of 10,000 minors (aged 0–18 years)

Table 3

**Eligibility Criteria for PPC (Modified From [Jankovic 2019]). PPC should be Provided when Any of the Following Eligibility Criteria are Met**

- Diagnosis of a life-limiting/threatening condition
- Serious episodes of hospitalizations:
  - at least three hospitalizations for serious clinical crises over a period of 6 months;
  - hospitalization of over 3 weeks without clinical improvement according to the medical team;
  - admission to intensive care of over 1 wk without clinical improvement
- Use of invasive medical devices for life support
- Life-threatening condition that causes difficulties in the management of pain or other symptoms
- Life-threatening conditions and complex psychosocial and spiritual needs of the child and family, including, but not limited to:
  - limited social support
  - the simultaneous need for more than three specialized services
  - a child with difficult and complex management of care handover between the hospital setting and the home
- Difficulties in making significant decisions for children and/or family:
  - difficulties in achieving consensus between the child, family and medical team on treatment and goals of care (e.g., resuscitation, use of parenteral nutrition/IV hydration or continuation of chemotherapy in the terminal stages)
- The anticipation of special support during the mourning period

Table 4  
Levels of Care of PPC Programs

Level	Description	Example of Providers Involved
1 – Palliative approach	Palliative care principles should be applied to all children with life-threatening/life-limiting conditions with low complexity needs of care regardless of where they are being cared for	All healthcare providers dealing with a situation in which PPC is required
2 – Generalized pediatric palliative care	Children and their families should benefit from the expertise of healthcare professionals who have basic training and experience in pediatric palliative care, without being fully engaged in PPC	Community pediatricians, hospital pediatricians, pediatric oncologists, pediatric neurologists, family doctors, nurses, social workers and psychologists involved in PPC
3 – Specialized pediatric palliative care	Specialized PPC services should be provided by an IDT of health and social care providers who work exclusively in a PPC setting and should assume the care of families of children with complex needs	Healthcare professionals specifically working in PPC in a dedicated setting

suffered from a disease eligible for PPC, with an annual mortality of 1 out of 10,000 minors.<sup>42</sup> More recent data show increased estimates: an English study reported a prevalence of 32 cases per 10,000 in 2009–2010, and 66.4 per 10,000 in 2017/2018, which is estimated to rise to 84.2 per 10,000 by 2030.<sup>43,44</sup> Of these children, approximately 85% are affected by nononcological conditions.<sup>43</sup>

These figures are likely to increase over the next decades.<sup>2,6,18,41,45,46</sup> However, the lack of data homogeneity, the diverse methods of data collection (prevalence vs. incidence, with prevalence being more challenging to estimate than incidence since the latter is estimated only upon the child's death) and the heterogeneity of eligibility criteria for PPC adopted by different countries, make estimations a challenging process.<sup>18,47</sup>

Among the children eligible for PPC worldwide, most of them live in low–middle-income countries (LMIC).<sup>2,6,19</sup> This finding is of utmost importance, given that PPC programs are currently lacking in many LMIC.<sup>2,48–51</sup> Of note, a 5% increase in PPC needs is expected by 2060 only in LMIC.<sup>7</sup>

Consequently, more specific estimations about PPC needs worldwide remain an urgent unmet need. Such estimation would allow for a proper allocation of resources, the definition of general and specialist PPC services, and the development of appropriate educational programs by healthcare providers and policy-makers.

Moreover, the spectrum of illnesses that render pediatric patients potentially eligible for PPC is wide and heterogeneous.<sup>33</sup> These illnesses include neurological, muscular, oncological, respiratory, cardiologic, metabolic, and chromosomal disorders as well as syndromes, malformations, infections, and post-anoxic conditions with non-oncological disease accounting for the majority of cases (cancer only accounts for 4.1%).<sup>33,52</sup>

Remarkably, children with HIV/AIDs in LMIC and congenital disease in high-income countries account for about half of the total number of children needing PPC, followed by children with extreme prematurity and birth trauma, and those with neurological conditions.<sup>2,6,41,44,52</sup> Therefore, dedicated training for the life-limiting and life-threatening conditions that make children eligible for PPC should be ensured for healthcare students and the life-long training of practitioners.

Several children also lack a definite diagnosis: it is important to consider evaluating eligibility for PPC, according to the criteria summarized in [Table 3](#).

## Standards

### Needs

#### Standards

- Healthcare providers should evaluate the specific needs of the child and their family and define a care plan and priorities accordingly
- The evaluation of needs should be global, taking into account clinical, psychological, social, organizational, educational, spiritual, cultural and ethical needs of the child and family
- The evaluation of needs must take into account the situation of the child and family, but also the foreseeable needs, wishes and desires, and those 'hidden' (i.e., those covered or unaddressed by the child and family during consultations)
- 'Hidden' needs can be unmasked by actively listening to the child and their family

A plan for PPC has to fulfill the needs of both the child and their family members by defining interventions that assess and effectively address their physical, psychological, social, spiritual and ethical concerns and

needs. It is important to underline that the planning and implementation of each intervention must balance any risk and benefit by taking into account the child's and family's quality of life, as well as the availability of resources and local possibilities. Ethical reflection on the choice of treatment must be imperative for all healthcare professionals.<sup>53</sup>

### *The Child's Needs*

#### **Standards**

- PPC should address the physical, psychosocial, spiritual and developmental needs of a child
- Distress caused by the disease should be minimized in order to improve the quality of life for the child and family
- Symptom control should be adapted to the child's age, setting and culture
- All interventions, either pharmacological or nonpharmacological, should be continuously monitored
- Evaluation, treatment, monitoring of symptoms and all other needs should be performed by qualified healthcare providers within an interdisciplinary team
- All PPC plans should be shared with the child, if possible, and their family

Child's needs can be categorized into clinical, developmental, psychological, social and spiritual, although there is much overlap among them.

The standards of care defined for the above—mentioned areas of intervention are listed below. A more detailed description of each area is reported in [Appendix A](#).

#### *Clinical Needs.*

#### **Standards**

- Preventing, alleviating, or eradicating distressing symptoms is one of the main goals of PPC
- Evaluation, treatment and monitoring of physical symptoms should be performed according to the specific response of each child
- The perceived impact of each symptom on the child's functioning and daily life should be regularly evaluated

#### *Developmental Needs.*

#### **Standards**

- PPC plans must take into account infants', children's and adolescents' developmental needs which are affected by their life-threatening and life-limiting condition

- PPC providers should be aware of how children's and adolescents' developmental stages affect how they cope with illness, dying, and death
- Members of the PPC team must have the competence to relate with infants, children and adolescents according to their cognitive, emotional, social, and physical stages of development
- Comprehensive transition procedures for adequate referral of adolescents from PPC teams to adult teams should be planned

#### *Psychological and Social Needs.*

#### **Standards**

- Children with serious illness or facing the dying process should be helped to cope with a range of feelings, thoughts and behaviors reflective of their anxiety and distress
- Psychological concerns and needs should be evaluated where possible by trained specialists within the multidisciplinary team, or, if these are not available, by individuals trained in psychological care
- Suitable psychosocial tools should help identify children's difficulties and plan appropriate interventions (verbal, symbolic, play, or art therapy)
- Approaches that foster the child's resilience should enhance self-esteem and promote autonomy
- PPC providers should actively listen and decode non-verbal language when communicating with children
- Parents should be helped to function effectively in their parenting role
- The child's social abilities (right to play and have fun, to attend school, to maintain relations with friends) should be promoted and adapted to their developmental age and physical condition

#### *Spiritual Needs.*

#### **Standards**

- Spiritual support should be provided to every child who wishes to discuss spiritual issues and concerns
- It is essential to maintain a respectful attitude towards the child's and family's cultural and spiritual/religious background

#### *Family Needs*

#### **Standards**

- Parents and other family members who have a close bond with the child should be involved in all care steps

- The assessment of family needs should begin at the initiation of PPC and be extended up to bereavement after the child's death
- The needs of family members (parents, siblings, grandparents, other persons if necessary) should be evaluated throughout the child's illness trajectory
- The families' needs should be included in the development of the PPC plan and addressed, when possible, by interdisciplinary team members skilled in active listening and communication and respectful of each family member's dignity

A pediatric life-limiting or life-threatening illness has traumatic effects on family members: family dynamics and roles, future aspirations and hopes often change.<sup>54–56</sup> Stressors may include emotional, psychological, social and financial challenges caused by the amount of time and responsibilities associated with one's caregiving role, the coordination of care and the management of altered family dynamics.<sup>57–59</sup> Families may also experience physical, social isolation and/or exclusion from their work setting or career.<sup>60</sup> Some parents express difficulties in accepting the diagnosis and prognosis of the disease and experience increased levels of anxiety about the child's future. Under extreme conditions, they may compromise or neglect child care.<sup>61</sup>

The needs of children and families are dynamic and constantly evolving. Therefore, it is important to assess and adjust the effectiveness of interventions regularly.

The standard of care regarding the most relevant family needs is presented below. For a detailed description, see [Appendix A](#).

#### *Communication Needs.*

##### **Standards**

- Honest, continued and open communication with the family is crucial
- Communication and discussions about the child's diagnosis and prognosis should take place in an appropriate and safe setting, taking into account the culture of the child and the family
- Parents should be assisted in maintaining their parental role and effectively addressing children's distressing behaviors

#### *Psychological Needs.*

##### **Standards**

- Family members should be offered the opportunity to share and discuss their personal feelings and thoughts, and receive appropriate support from compassionate professionals with advanced communication skills
- Potential situations of conflict should be identified early, prevented, and managed

- Trained members of the interdisciplinary team should offer psychological support to family members, and when possible, by specialized mental health professionals, especially when distress is very high, abuse occurs, and dysfunctional family dynamics perpetuate over time
- Psychological support should be available to all family members after the death of the child and, when possible, for as long as needed

#### *Need for Home Care and Organizational Support.*

##### **Standards**

- Parents and other family members should be trained and supported 24/7 in caring for their child at home whenever possible
- They should be assisted in maintaining their social roles (e.g., work, future perspectives)
- Economic issues should be investigated and addressed if possible

#### *Siblings' and Grandparents' Needs.*

##### **Standard**

- Siblings' and grandparents' concerns and needs should be addressed
- Support should be provided to them throughout the child's illness and death, given that their suffering is often underestimated

#### *Ethical Needs*

##### **Standards**

- Each decision should be taken according to the four basic ethical principles: best interest principle, risk-benefit proportionality principle, distributive justice, autonomy
- Each decision of care should be based on the principle of the "child's best interest", as shared between the patient, family and clinician

Each decision in PPC should be based on the four basic ethical principles: Best interest principle, Risk-benefit proportionality principle, Distributive justice, Autonomy. In particular, the principle of what is in the "child's best interest" should be intended as the respect of children's rights and special needs for their protection and development. By supporting this child-centered and family-oriented process, shared decision-making becomes crucial in implementing the best interest standard in a coherent framework and process that is referred to as the "shared optimum



approach.”<sup>62,63</sup> This is intended as a responsibility of the patient, family members and health professionals.

A more detailed discussion about the standard defined for the ethical needs is provided in [Appendix A](#).

### *Advanced Care Planning*

#### **Standards**

- ACP discussions should continue throughout the disease trajectory as much as possible, and may include, but are not limited to: the wishes about the care of the child, the definition of the goals of care and reconsideration of goals when the child's health worsens, plans about “what to do” in case of emergencies, and end-of-life care. All options should be kept open and revised regularly
- Specific guidelines for ACP should be established in each institution
- Healthcare professionals should receive proper training in ACP

Advance care planning (ACP) in PPC is a structured model that enables the determination of goals and preferences for future medical treatment, and the place of end-of-life care and death.<sup>64</sup> In some cases, initial goals may no longer be applicable. In these cases, the initial goals should be discussed, and new goals should be generated, such as maintaining the child's quality of life, for example, by deciding the location of the child's end-of-life care and death.<sup>65</sup> For more details about the ACP and related standards, see [Appendix A](#).

### *End-of-Life Care*

#### **Standards**

- During the entire disease course, the possible evolution of the disease should be discussed
- The end-of-life and its setting should be prepared and defined according to the wishes of the child, the family, and available resources
- Distressing physical and psychological symptoms should be addressed and treated
- The child's dignity must be respected by ensuring an appropriate environment and the presence of loved ones
- Spiritual and religious services, appropriate to the family's beliefs and practices, should be offered before and after death
- Children at the end-of-life should be cared for by trained healthcare providers and, when possible, by an interdisciplinary team
- The family should be prepared for physical changes associated with the dying process

- The family should have time to properly say goodbye to the child according to their spiritual and family culture/religious practices
- Siblings must be granted adequate time with the dying child
- The body should be treated with due respect and with extreme attention and care according to the family's culture and religious practices
- Healthcare providers must respect all different strategies of coping with loss
- Bereavement support should be offered to the family for as long as needed, within the resources available

There is no standardized definition for “end of life” in children. Therefore, it is important to share with the family the possible evolution of the disease, communicate the diagnosis of incurability and tackle the concept of terminal illness and death. A more extensive discussion on this topic is provided in [Appendix B](#).

### *Care Models and Settings of Care*

#### **Standards**

- PPC offered by trained healthcare providers should be ensured to all eligible children and their families, regardless of their financial or health insurance status
- Each child and family must have a defined person of contact for PPC, who should coordinate the care plan
- The support of a specialized PPC team should be available continuously, when possible all days of the year, 24/7
- PPC should be offered in all settings of the child's life (home, hospice, hospital, school), by ensuring continuity of care
- The gold standard for the place of care is where the child and family want to be and feel the most supported
- The PPC team will ensure that children's symptoms are assessed and managed appropriately
- If necessary, respite care should be made available for families or other caregivers
- Telemedicine should be integrated into current care models according to local resources
- Perinatal Palliative Care (PnPC) should be considered in routine obstetrics and neonatal care
- Hospitals providing neonatal and maternal care need to develop PnPC pathways
- PnPC may be provided in the delivery room, post-partum ward, in the neonatal intensive care unit (NICU), at home, or wherever is thought to be most appropriate and provided this approach is consistent with family goals of care

- For critically ill children with an unknown diagnosis, goals of care, and potential incurability, professionals in the emergency department should evaluate the clinical situation and contact PPC teams
- The PPC team should be supported to ensure self-care and prevent burnout

PPC offered by trained healthcare providers should be ensured to all eligible children and their families, regardless of their financial or health insurance status. Furthermore, each child and family must have a defined person of contact for PPC. This requires the development of proper models of care in every PPC setting, with the additional aim to ensure coordination and continuation of care.<sup>66</sup> When children experience different settings of care because they present different needs, coordination of care becomes essential. This involves the integration of the different care settings, thus overcoming the fragmentation that the management of different needs frequently causes. The aim here is to improve the overall quality and continuity of care, intended as the coverage of needs in the various care and life settings, and to encourage the possibility of making shared care choices.<sup>67-70</sup> The presence of a specific and dedicated team favors a dynamic and fast response to any change in the history of the disease and the resulting needs of children and families, offering a continuous point of reference that concentrates on skills/relationships/tools appropriate to the different situations. Receiving adequate coordination of care was also associated with more favorable family/care-provider relations and family/child outcomes.<sup>71,72</sup> According to the WHO, PPC requires “a broad interdisciplinary approach.” Therefore, any hospital or healthcare organization that frequently assists children eligible for PPC should have an interdisciplinary PPC team (IDT).<sup>3,73</sup> When this is not possible, due to organizational issues or very limited resources, PPC should be delivered by healthcare professionals with the highest possible levels of training. The role of “non-medical clinicians,” such as community health workers, volunteer clinicians, home care nurses, and midwives, is also crucial.<sup>74</sup> Moreover, PPC should be implemented in every setting where pediatric care is provided, including obstetrics, neonatal care, intensive and emergency care.

The models of PPC that should be implemented are discussed in [Appendix C](#). The standards defined for the provision of PPC in the Neonatal Intensive Care Unit (NICU), Pediatric Intensive Care Unit (PICU) and emergency department are also presented. Some other settings are not specifically discussed (e.g., long-term facilities, community health clinics), but proposed standards can – and should – be adapted accordingly to specific situations.

## PPC in Humanitarian Emergencies

### Standards

- PPC should be made available during all humanitarian emergencies
- PPC in humanitarian crises should be integrated into each country’s healthcare system
- PPC activities must be included in the planning and implementation of the social and health response
- Guidelines about education and mentorship should be provided to health care providers
- Essential pediatric palliative care medications should be available in humanitarian crises
- The child/family relationships should be ensured as much as possible during an emergency, using all appropriate tools
- PPC staff working in humanitarian settings should be properly supported and protected

The WHO recommends implementing Palliative Care during humanitarian emergencies such as natural disasters, war, conflict, and famine.<sup>31,75</sup> More than 128.6 million people across 33 countries require life-saving humanitarian assistance, 92.8 million of whom are particularly vulnerable, with many being children.<sup>76</sup> PPC standards defined for humanitarian emergencies are discussed in [Appendix D](#).

### Care Tools

### Standards

- Standardized tools, when possible, validated for the specific language and culture of the child and the family, should be used in order to assess and measure the needs of children and families; the PPC plan must be reconsidered accordingly
- The development of tools to objectively measure the PCC program’s effectiveness should become a priority
- The tools to assess the needs of the child and family should preferably be based on a multidimensional approach that is culturally adapted
- The assessment tools and the outcomes of the evaluation should be available to all professionals of the interdisciplinary team

Outcome monitoring is essential in PPC. Therefore, there is the need to use standardized and validated tools, when possible validated for the specific language and culture of the child and the family, in order to assess and measure the needs of children and families. Such tools help professionals assess and measure the needs of children and families, the services and programs implemented to patients with different diseases, and the setting in which the PPC interdisciplinary team

operates.<sup>28,77–79</sup> Appendix E reports a detailed discussion about a few tools available to assess the child's needs in PPC and family members. An in-depth description of each tool goes beyond the scope of the present article. Noteworthy, not all tools are validated for use with a pediatric population and this should be taken into account when selecting “the most suitable tool” for a specific situation.

### *Education and Training for Healthcare Providers*

#### **Standards**

- PPC education must be a core part of all pediatric healthcare professionals
- Interdisciplinary education should be promoted, with members of different disciplines learning interactively to improve interprofessional collaboration and the well-being of patients
- Curricula (goals and competence) should be adapted to the three levels of PPC provision: the palliative approach by all healthcare providers (1st level); the generalized pediatric palliative care education (2nd level); and the specialized pediatric palliative care education (3rd level)
- Education should provide knowledge, skills, development of attitudes appropriate to the PPC principles, as well as the implementation of interprofessional practice and abilities for self-awareness and proactive practice.
- Specialist PPC competencies should further include PPC advocacy, leading and developing services, policymaking, service evaluation, conduction of PPC research and engagement in training and education
- Every country must develop specific education curricula for all professionals in PPC
- Referral centers and academic institutions for specialist PPC education must be identified

PPC encompasses multifaceted requirements, from the clinical management of different conditions to handling complex communication, psychological, and spiritual issues. Therefore, education should be mandatory both at an undergraduate and a post-graduate level, whereas training for all healthcare providers should be available.

Standards in this regard are listed above and discussed in Appendix F.

### *Areas for Improvement*

The goal of PPC is to improve the life of eligible children and their families by offering competent and interdisciplinary assistance, which takes into account the dignity of the person. However, a major gap remains between what should be done and what is actually being done in clinical practice.

Several areas should be addressed and developed, and legislation should be ensured for the provision of PPC, which must be included in the healthcare system of every country

Given that PPC is not equally available in all countries, the most immediate interventions must address the disparity of PPC delivery, the availability of essential drugs and care tools worldwide, especially in LMIC. This goal requires collecting and sharing data, strategies, and tools to evaluate the magnitude of the PPC need worldwide based on well-defined eligibility criteria. This evaluation can also guide a proper allocation of resources. Research is also necessary to assess the efficacy of current therapies and devices and develop new effective care tools.

We also need efforts to define specific approaches in different settings and identify indicators for assessing the quality of standards and processes. A proper assessment of the application of the presented standards in each country may help identify areas for improvement, for the implementation of new care models, and for the establishment of networks to share experiences and solutions. The econometric analysis will allow us to identify the most sustainable models of PPC in each specific scenario. To achieve these goals, it is of utmost importance to allocate adequate resources to investigators, with a special focus on the involvement of younger researchers. The role of new technologies and tools (telemedicine, robotics) should be evaluated and implemented with the aim to reach all children eligible for PPC and their families.

Another major need is the development of proper education curricula at both undergraduate and post-graduate levels, as well as programs for life-long training for professionals who provide services to seriously ill children. Furthermore, correct information for the community should be offered to all communication media, including social networks, in order to reach the widest possible audience, especially the youngest.

Different players are involved in the PPC: patients, families, healthcare providers, institutions, and non-profit organizations. Therefore, it is crucial to establish a network of experts, families, institutions (e.g., WHO Human Resources for Health) and non-profit organizations to ensure the sharing of data, strategies, and educational programs. In particular, we believe that the role of non-profit organizations should be expanded by promoting their closer cooperation with healthcare providers and institutions. On their side, policymakers must take the responsibility to ensure the widest availability of essential drugs and devices worldwide, so as to overcome any inhomogeneity for every child's right to be cured.

Last, the authors advocate that the implementation of quality indicators for PPC becomes a requirement and priority of all governments across the world, and is

measured as an indicator of the quality of health care and, above all, an indicator of respect for the dignity of the person, specifically the child.

### Conclusion

Since the publication of the IMPaCCT project, much effort has been made in the development of new approaches to PPC. Hence, 15 years later, it is time to redefine the standards in PPC. Here, we have expanded and updated the previously published IMPaCCT standards to include new practices (e.g., ACP) and new standards for applying PPC in perinatal care, in humanitarian crises, and other specific settings and conditions (e.g., intensive care).

We believe that the present document, developed with the contribution of an international group of experts from different countries, experiences and models of care, provides standards for a wider implementation of PPC worldwide. We are aware that the standards we present were developed by consensus among international Experts and are not based on a formal, systematic evaluation of available studies. However, a systematic review approach or more structured consensus techniques (e.g., a Delphi round) may be applied to the single topics presented, when feasible. These can be the subject of future, more focused studies. Indeed, this document can represent the starting point for triggering research and systematic evaluations in the various areas of PPC.

An increase in the number of children eligible for PPC is expected over the next 15 years, and therefore, we will face several major challenges. Legislation, education, exchange of information about best practices are the essential tools to improve PPC worldwide.

### Author Contributions

All the Authors contributed to the literature research. FB, LG and SP wrote the first draft. All other Authors have critically contributed to the analysis of evidence and provided major intellectual input to the paper. All Authors have read and approved the final version of the paper before submission.

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### Supplementary materials

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