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Paediatric oncology meets palliative care: A road towards a common language

Lucia De Zen [a,*], Marta Giorgia Podda [b], Maria Aviles Martinez [c], Georgia Kokkinou [d,e], Kerstin Krottendorfer [f], Ana Lacerda [g]

[a] Pain and Paediatric Palliative Care Center, Institute for Maternal and Child Health - IRCCS "Burlo Garofolo" – Trieste, Italy
[b] SC Pediatria Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Italy
[c] Department of Nursing, Faculty of Nursing, Autonomous University of Madrid, Spain
[d] Floga Parents Association of Children with Cancer, Athens, Greece
[e] CCI-Europe
[f] Department of Pediatrics and Adolescent Medicine, Medical University of Vienna, Austria
[g] Departament of Pediatrics, Portuguese Institute of Oncology, Lisbon Centre, Lisboa, Portugal

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ABSTRACT

Advances in paediatric oncology (PO) have substantially improved survival rates in childhood cancer, yet an increasing complexity has generated new clinical, psychosocial and ethical challenges. Integrating paediatric palliative care (PPC) early in the oncological trajectory has been shown to enhance quality of life for patients and families, but conceptual barriers often hinder collaboration between the two disciplines. This project aimed to develop a shared European glossary of key terms used in PO and PPC, fostering a common language to facilitate communication, collaboration and integration across culturally and resource diverse healthcare systems. Building upon an existing Italian glossary, a European version was developed in 2024. The process included English translation, expert review and multiple consensus rounds involving representatives from the European Society for Paediatric Oncology (SIOPE) PPC Working Group and the Italian interdisciplinary team. Each term was critically evaluated for conceptual clarity, cross-cultural applicability and alignment with international practice. The glossary evolved from 30 to 21 final terms, reflecting consensus on definitions and the removal or adaptation of items not generalizable to the European context (e.g., terms linked to Italian legislation). The final document underwent editorial and graphical revision, and was submitted to the SIOPE Executive Board for endorsement and dissemination. The European Glossary of PO and PPC provides a foundational framework for harmonising language and practice across Europe. It supports education, clinical integration and policy dialogue, representing a key step towards shared understanding and patient-centred care for children with cancer and their families.

1. Introduction

Over the past decades, the field of paediatric oncology (PO) has achieved remarkable advancements, significantly increasing survival rates [1]. Recent advances in systemic anticancer treatments, including immunotherapy and targeted therapies, have extended survival for incurable cancers [2,3] but introduced complexity and unpredictability in illness trajectories [4] which may now include temporary improvement, prolonged response, or rapid decline. When disease trajectories are further complicated by adverse events such as toxicity, relapse or incurability, the complexity of care intensifies.

As prolonged and complex treatment pathways give rise to additional clinical, psychological, social, spiritual and ethical challenges, the need for personalised care and early integration of supportive and palliative services is underscored [5,6]. In such scenarios, collaboration between PO and paediatric palliative care (PPC) becomes essential. International literature highlights the profound impact of this synergy, showing that early collaboration between the two disciplines significantly improves quality of life for both patients and their families [7]. Yet, despite these clear benefits and patient/family acceptance [8], barriers to integration persist, including a lack of mutual understanding, undefined roles, and cultural resistance to early palliative interventions

* Correspondence to: Pain and Paediatric Care Center, Institute for Maternal and Child Health - IRCCS "Burlo Garofolo", via dell'Istria 65/1, Trieste 34137, Italy.
E-mail address: lucia.dezen@burlo.trieste.it (L. De Zen).

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[9].

Recognising these challenges, the Italian Association of Paediatric Hemato-Oncology (AIEOP), the Italian Society of Paediatrics (SIP), and the Italian Society of Palliative Care (SICP) joined forces to create an interdisciplinary group of paediatricians, nurses and psychologists. The group prioritised establishing a common language between the two disciplines as a foundational step towards integration. Through expert dialogue, a comprehensive glossary was developed, defining 30 key terms to facilitate communication and collaboration [10]. By bridging the gap between PO and PPC, they hoped to provide the framework for a truly holistic model of care, where treatments effects and quality of life are balanced.

Also at European level, there is an urgent need to improve palliative care for children affected by cancer. Major barriers might be found in 1) the lack of resources, 2) the lack of PPC programmes and workforce at the health systems level, 3) difficulties in integrating PPC into existing PO care models, and 4) the lack of knowledge about PPC. Recently, European Commission financed a programme for the Union's action in the field of health ('EU4Health Programme') to promote a joint action with the objective to ensure the access to PPC for children affected by cancer. [11].

So, the importance of the Italian tool was recognised by others, and the group received a proposal for a Europe-wide adaptation. This effort included translating the glossary into English and refining its content to remove terms and definitions closely linked to the Italian context, making it applicable across diverse healthcare systems and cultural settings. In this paper we share this process, aiming to further promote the glossary, fostering broader awareness and adoption of a shared language to advance the integration of PO and PPC.

2. Methods

The development of the European version of the PO and PPC glossary followed a progressive, multi-step process characterised by close collaboration between the Italian interdisciplinary group and the European Society for Paediatric Oncology (SIOPE) PPC Working Group (WG) (Fig. 1).

The idea of a shared initiative first emerged when the leader from the SIOPE PPC WG approached the Italian group to explore the possibility of adapting the Italian glossary to a broader European framework. The proposal was discussed within both groups, where members expressed a strong interest in pursuing a collaboration. This was followed by a formal agreement, establishing the foundation for joint development.

The Italian glossary had been produced by a group of 12 experts in PO and PPC, belonging to different Italian scientific societies (AIEOP, SIP, SICP). Particular attention had been given to ensuring heterogeneity and balance within the original group in terms of age, gender, professional background (including physicians, nurses, and psychologists), professional experience, and geographical area of practice.

The first step was taken by the Italian team delivering the English translation of the original glossary, to serve as the basis for the European adaptation.

Within SIOPE PPC WG, an interdisciplinary panel of four experts was assembled, looking to provide a diverse representation regarding disciplines and national backgrounds. The panel consisted of a social worker, a patient advocate (who is also a linguist), a senior oncologist and a specialist PPC nurse. Meanwhile, the Italian group appointed two representatives—a senior oncologist and a senior PPC specialist— to accompany the project (Fig. 2).

Following the initial SIOPE experts' review, some terms were maintained, some were modified or merged (Appropriateness of care, Pain, Individual Care Plan, Terminality/End-of-life), and others excluded because they were considered too specifically related to the Italian healthcare or legislative framework (Home base PPC, PPC network, Pain and PPC Regional Centre, Taking charge) or not relevant (bioethics, child, family (Fig. 1). Some other terms were added (End-of-life care, Terminal care). The list of terms to be included in the European version was collectively selected and discussed.

This step aimed to preserve conceptual accuracy while making the terminology accessible and relevant in different cultural and legislative contexts.

Consequently, the glossary was refined to include only broadly

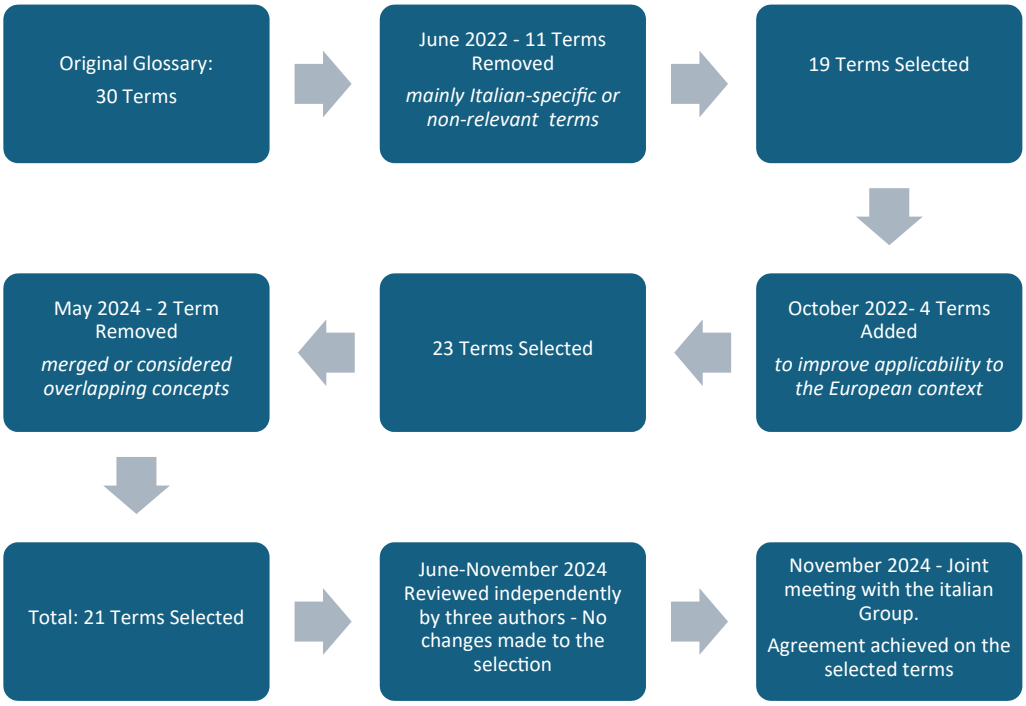

Fig. 1. Adaptation process from the Italian glossary (30 terms) to the European glossary (21 terms). Table 1 provides detailed information regarding the terms that were maintained, merged, modified, excluded, or introduced during the adaptation process, together with the rationale underlying these decisions.

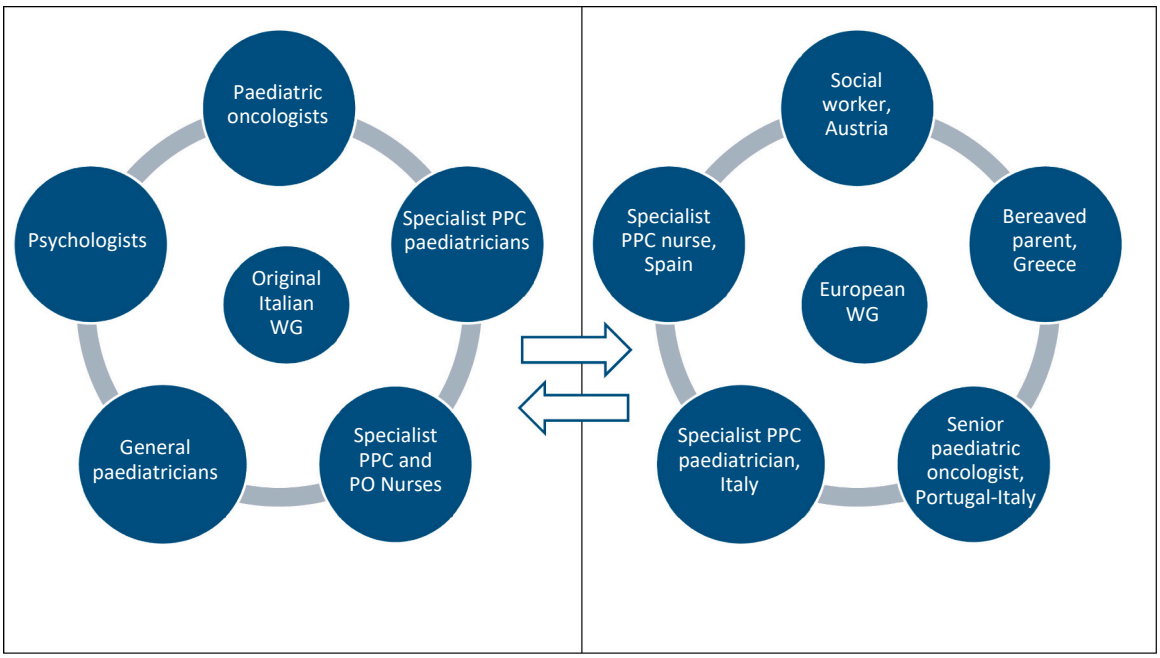

Fig. 2. Structure of the Italian and SIOPE working groups that developed and adapted the glossary - interdisciplinary and complementary (PPC: Paediatric Palliative Care; PO: Paediatric Oncology.

applicable key terms, each reviewed and discussed to align with international standards [12]. During this stage, certain terms were modified for conceptual clarity—for example, "Individual Care Plan" was replaced with "Advance Care Planning", reflecting the mostly internationally used contemporary terminology.

The subsequent consensus process was conducted between June and November 2024, to reach agreement on scope and definitions. The review involved multiple iterative rounds and four all-expert meetings. The individual feedback and collective discussions followed an iterative expert discussions aimed at reaching consensus within the multidisciplinary working group. Definitions and terms were iteratively discussed among members until a shared agreement was reached.

When disagreements emerged, these were managed through further review and discussion of the available literature supporting the different definitions or interpretations of the term. The working group then rediscussed the terminology in light of the scientific evidence and the practical applicability across different European contexts, with the aim of reaching a shared and clinically meaningful definition.

Throughout this process, the number of terms was gradually refined.

A definite consensus was reached in November 2024, during a joint meeting between the SIOPE expert panel and the Italian representatives. The group approved the final version of the European Glossary of PO and PPC, as representing a fully harmonised and culturally adaptable resource.

In the following months, the document underwent further editorial and graphical revision, ensuring linguistic consistency, readability and visual coherence with SIOPE standards, with a translation process involving back and forth translation. The finalised version was then submitted to the SIOPE Executive Board for formal endorsement and dissemination within the network.

3. Results

From the initial 30 items, a final version including 21 items was developed with some excluded as specifically linked to Italian legislation and others merged or redefined for clarity.

To improve transparency regarding this adaptation process, we have also clarified in Table 1 the rationale underlying inclusion, exclusion, merging, or modification of terms during the transition from the Italian to the European version of the glossary.

In supplementary material we present the original Italian (S1) and the European (S2) glossaries.

4. Discussion

4.1. The need for an integrated model of care

Over recent decades, paediatric oncology has achieved remarkable progress, significantly improving survival for many childhood cancers [1]. Novel therapies, including immunotherapies and targeted treatments, have transformed disease trajectories, which may now range from cure and long-term remission to unexpected relapse and treatment-related complications [2–5]. While these advances have improved outcomes, they have also increased the complexity of care, exposing children and families to prolonged uncertainty, treatment burden, and reduced quality of life [6,13].

These evolving trajectories require a model of care that extends beyond disease-directed treatment and addresses the psychological, social, spiritual and ethical dimensions of illness [14]. In particular, when cure is no longer possible, clinicians must balance disease-directed interventions with comfort, dignity and quality of life, ensuring that care remains proportionate and aligned with the child's best interests [7,15].

4.2. Benefits of and barriers to the integration of PPC into PO

Within this context, the integration of PPC into PO has become increasingly recognised as both a clinical and ethical necessity [11,16]. Evidence shows that early PPC involvement improves symptom management, communication, decision-making, psychosocial support and quality of life for children and families, while also supporting families during bereavement [17–20].

Despite these benefits, integration remains inconsistent across Europe. Barriers include limited understanding of PPC within oncology, uncertainty regarding roles and responsibilities, organisational constraints, and the persistent misconception that palliative care is synonymous with end-of-life care [18–26]. Differences in terminology

Table 1
Terms discussed in the process of adaptation from the Italian into the European version of the glossary.

All terms	Italian glossary	European glossary	Notes
Advance Care Planning	✓	✓	Changed from "Shared care planning" and merged with "Individual Care Plan"
Appropriateness of care	✓	–	Merged with "Proportionality of care"
AYA (adolescents and young adults)	✓	✓	
Bioethics	✓	–	Deemed not relevant in this glossary
Care needs and complexity	✓	✓	
Child	✓	–	Deemed not relevant in this glossary
Continuity of care	✓	✓	
Early palliative care and shared care	✓	✓	Original "Early palliative care and simultaneous care"
Eligibility for PPC	✓	✓	Originally "Eligibility for PPC/ PPC referral criteria"
End of life care	–	✓	Originally "Terminality / End of life"
Family	✓	–	Deemed not relevant in this glossary
Home based palliative care	✓	–	Italian specific definition
Incurability	✓	✓	
Individual Care Plan	✓	–	Merged with "Advance Care Planning"
Informed Consent	✓	✓	
Integrated Home Care	✓	✓	Originally "Integrated Home Care Services"
Paediatric hospice	✓	✓	
Paediatric palliative care	✓	✓	
Paediatric Palliative Care Network	✓	–	Italian specific definition
Paediatric palliative care Team	✓	✓	Originally "Specialized PPC Team"
Pain	✓	–	Included in Total pain
Pain and PPC Regional Centre	✓	–	Italian specific definition
Palliative chemotherapy	✓	✓	
Palliative radiotherapy	✓	✓	
Palliative surgery	✓	✓	
Proportionality of care	✓	✓	
Quality of life	✓	✓	
Taking charge	✓	–	Italian specific definition
Terminal care	–	✓	Originally "Terminality / End of life"
Terminality / End of life	✓	–	Divided into "Terminal care" and "End of life care"
Therapeutic disproportion / persistence	✓	✓	
Total Pain	✓	✓	

between disciplines may further hinder collaboration and delay PPC involvement.

The development of a shared language can help overcome these challenges [27]. By clarifying concepts and definitions, the glossary may facilitate communication, improve continuity of care, reduce misunderstandings and support earlier collaboration between teams [28].

4.3. Towards a shared European framework

The European glossary was developed to promote a common conceptual and linguistic framework between PO and PPC. Harmonising terminology can support collaborative care planning, education, research and policy development while facilitating communication across different healthcare systems.

The adaptation process involved professionals from multiple disciplines and countries, as well as family representation, ensuring that the glossary reflects diverse perspectives and experiences. Differences in professional background, healthcare organisation and cultural context inevitably influenced the interpretation of some terms. For this reason, definitions were discussed through an iterative consensus process aimed at achieving shared and clinically meaningful terminology.

4.4. Challenges in defining terminology

Some concepts proved particularly challenging to define, especially those associated with strong cultural, ethical or legislative implications, such as terminality, end-of-life care and proportionality of treatment.

Definitions of end-of-life care vary across organisations and scientific societies, particularly regarding its distinction from terminal care in paediatric settings [29,30].

These discussions highlighted the need to balance conceptual precision with sufficient flexibility to allow applicability across different healthcare systems. The process demonstrated that developing shared terminology is not merely a linguistic exercise but also an opportunity for interdisciplinary reflection and integration.

4.5. A multidisciplinary and family-centred approach

A key strength of this initiative was its multidisciplinary nature. Professionals from paediatric oncology, palliative care, nursing, psychology and social work contributed to the glossary's development, ensuring that different perspectives were represented.

The involvement of Childhood Cancer International–Europe (CCI-E), through a bereaved parent who also contributed linguistic expertise, added an important family perspective. This contribution helped ensure that the glossary reflects not only professional consensus but also the experiences and expectations of children and families affected by cancer.

Such participation reinforces the importance of co-production and inclusivity in the development of care frameworks intended to improve the quality of care for children with serious illness.

4.6. Future directions

The glossary represents an important step towards greater integration between PO and PPC, but it should be viewed as a starting point rather than a final product.

Future efforts should focus on implementation within clinical practice, education and policy.

The glossary should also be considered a living document, open to future revision as clinical practice, evidence and international collaboration evolve. Translation into additional European languages and dissemination through SIOPE and other professional networks may further support adoption across healthcare systems.

Beyond its terminological function, the glossary may contribute to greater awareness of PPC and help challenge misconceptions that continue to associate palliative care exclusively with end-of-life care. In doing so, it may support a broader understanding of PPC as an integral component of high-quality, person-centred oncology care from diagnosis onwards.

5. Conclusions

The European Glossary of PO and PPC represents an important step towards a shared understanding between two disciplines that share the common goal of improving the quality of life of children with cancer and their families. Through the harmonisation of key concepts and terminology, the glossary provides a foundation for more integrated,

collaborative and patient-centred care across Europe.

The project also demonstrates the value of interdisciplinary and family-inclusive collaboration. The glossary may support clinical practice, education, research and policy development while fostering closer integration between PO and PPC. As a living document, it also offers a platform for future dialogue, refinement and implementation across different European healthcare contexts.

List of abbreviations

AIEOP: Associazione Italiana Emato-Oncologia Pediatrica (Italian Association of Paediatric Hematology-Oncology).

CCI-E: Childhood Cancer International–Europe.

PO: paediatric oncology.

PPC: paediatric palliative care.

SICP: Società Italiana di Cure Palliative (Italian Society of Palliative Care).

SIOPE: European Society for Paediatric Oncology.

SIP: Società Italiana di Pediatria (Italian Society of Paediatrics).

WG: Working Group.

CRediT authorship contribution statement

Marta Giorgia Podda: Writing – original draft, Visualization, Formal analysis, Conceptualization. **Maria Aviles Martinez:** Writing – original draft, Visualization, Validation, Supervision, Methodology, Conceptualization. **Lucia De Zen:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Methodology, Formal analysis, Data curation, Conceptualization. **Ana Lacerda:** Writing – original draft, Visualization, Validation, Supervision, Methodology, Formal analysis, Data curation, Conceptualization. **Georgia Kokkinou:** Writing – review & editing, Visualization, Validation, Supervision, Formal analysis, Data curation, Conceptualization. **Kerstin Krottendorfer:** Writing – review & editing, Visualization, Validation, Supervision.

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Declaration of Competing Interest

The author is an Editorial Board Member/Editor-in-Chief/Associate Editor/Guest Editor for this journal and was not involved in the editorial review or the decision to publish this article.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ejcped.2026.100540.

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