PALLIATIVE CARE
Working Group

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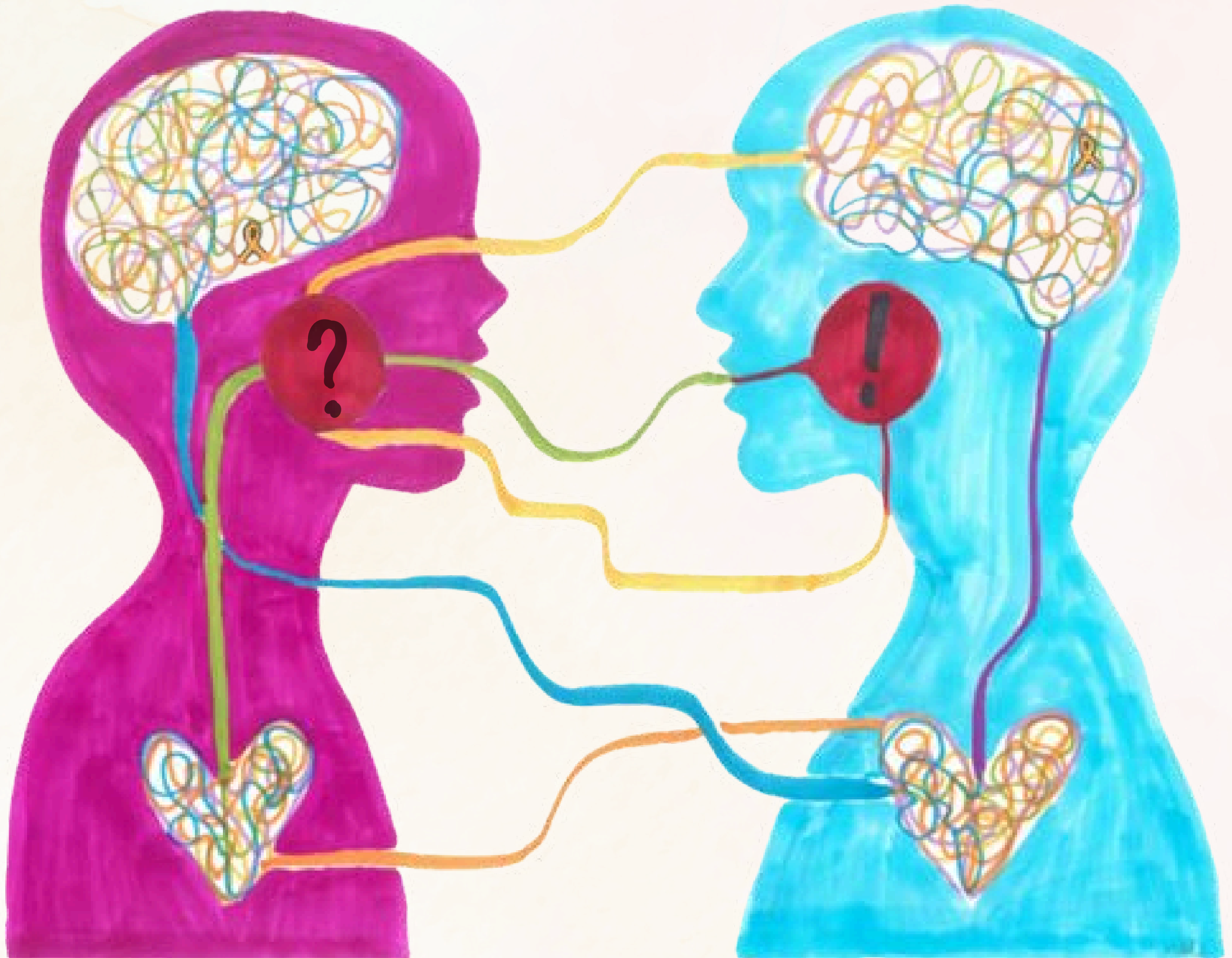
GLOSSARY OF TERMS

A Shared Language to Promote Integration

PAEDIATRIC ONCOLOGY & PAEDIATRIC PALLIATIVE CARE



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Paediatric oncology (PO) has achieved remarkable developments, significantly increasing survival while escalating complexity and unpredictability. In scenarios of prolonged and complex treatment pathways (adding clinical, psychosocial, spiritual, and ethical challenges), personalized care, integrated with paediatric palliative care (PPC), becomes essential. Evidence shows that early synergy between the two disciplines significantly improves patients' and their families' quality of life. Yet barriers persist, including a lack of mutual understanding, undefined roles, and cultural resistance to early palliative interventions.

In 2021, three Italian Associations (Paediatric Hematology Oncology, Paediatrics Society, and Palliative Care Society) came together to establish a common language as a foundational step towards integration. Through interdisciplinary experts' dialogue, a comprehensive glossary was developed, defining key terms to enable communication and collaboration.

The SIOPE Palliative Care Working Group suggested a European adaptation, making the glossary applicable across diverse cultures and healthcare systems.

We hope this tool will contribute to raising awareness and adoption of a shared language, ultimately advancing the integration of PO and PPC.

Below each explanation, you will find references or recommended reading.

SIOPE expert group

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Advance Care Planning	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. In some cases, initial goals may no longer be applicable - goals should be re-discussed, and new goals 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). *10.1016/j.jpainsymman.2021.12.031*
AYA (adolescents and young adults)	Adolescents are aged between 15-19 years, while young adults are aged between 20-39 years, regardless of sex, ethnicity, nationality and health condition. In the last decade, the definition of Adolescent and Young Adult (AYA) has been introduced in PO, acknowledging that many adolescents suffering from cancer share the same clinical and psychosocial problems as the young adults. Nonetheless, PO mostly focuses on patients up to the age of 18. *10.1016/j.esmoop.2021.100096*
Care needs and complexity	Care needs are about receiving assistance due to altered physical or mental conditions. The severity and features of the health problem, as well as the specific interventions required to manage it, determine the level of care complexity. Needs can be quantified using specific scales. Complexity is defined based on the child's and family's needs, and the type and number of resources required to meet those needs, including skills and competencies. *10.1089/jpm.2020.0148*
Continuity of care	Providing ongoing and comprehensive support to the child and family: • After identifying their needs; • In all settings (home, hospital, other); • Through continuity in the care plan (cooperation and communication between the required healthcare professionals and/or support networks). *10.1258/135581906778476490*
Early palliative and shared care	A timely integration of PPC through the illness of a child with an incurable or probably incurable disease (ideally since the time of diagnosis). The objective is the integration of possibly curative interventions (to heal/slow the disease) with palliative actions aimed at ensuring a good quality of life for the child and their family and a state of global "good health" even in illness (clinical/social approach). Early palliative care can be provided from the early stages of the disease, and, when started at the same time as curative treatments, it is called simultaneous care. If at diagnosis the disease is deemed probably incurable, simultaneous care requires the involvement of specialist PPC. https://www.iccp-portal.org/system/files/resources/Global_Atlas_of_Palliative_Care.pdf; 10.1016/j.jpainsymman.2021.12.031

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Eligibility for PPC	PPC should be provided when any of the following criteria are met: • Diagnosis of a life-limiting/threatening condition • Serious episodes of hospitalization • Use of invasive medical devices for life support • A 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 • Difficulties in major decision-making with the child and/or the family • Anticipation of the need for special support during the mourning period 10.1016/j.jpainsymman.2021.12.031
End of life care	Care for those who are deteriorating and approaching death, usually defined as the last 6-12 months of life. It aims to provide the best possible quality of life for those at the end of their lives, through integration of supportive and palliative care, alongside practical support. This includes revisiting care goals, and identifying and meeting the patient's and their family's needs. 10.1089/jpm.2022.0030; 10.1177/00302228221086058; 10.1016/j.jpainsymman.2013.02.021; 10.1002/cncr.32935
Incurability	When there are no other curative options and/or interventions for a life-limiting or life-threatening condition, ultimately leading to death. 10.1186/s13052-019-0681-3
Informed consent	The process by which the patient or their representative authorises a diagnostic/therapeutic intervention or programme. Informed consent for a minor is usually provided or refused by their parents or legal guardians, considering the minor's wishes and protecting their physical and psychosocial health and life, while fully respecting their dignity. However, the maturity of the child or young person can vary significantly depending on the age and stage of cognitive and intellectual development. This is why it is important to establish a relationship between the care team, the minor and their family. Communication should be based on clear and honest information, continuous dialogue, and open discussion, to protect the child's best interests and respect their wishes to the greatest possible extent. Involving and talking with children below consent age is encouraged, especially if they are cognitively capable. Depending on the jurisdiction, the minor's assent may also be required. Make sure to check the legal requirements and provisions in your country. 10.1093/bmb/ldac038
Integrated Home Care	Care provided at the family's home, based on an integrated multidisciplinary plan, ensuring continuity of care. The team providing the care can be hospital-based or not, depending on the healthcare system/country/region. It may include various professional aids, from nursing to rehabilitation, who deliver the set of multidisciplinary interventions devised in the care plan. The activation of the support requested by the Oncology team requires the involvement of the Palliative Care team and the General Practitioner / Paediatrician in defining the goals and care processes, through a multidimensional assessment. It is aimed at patients who, although they do not have specific criticalities or particularly complex symptoms, need continuity of care and scheduled interventions. 10.1016/j.jpainsymman.2021.12.031

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Paediatric hospice	An independent and autonomous alternative to the hospital, with a high care complexity, from a structural and organisational point of view, suitable for children, with age-appropriate spaces, places and furnishings. If existent, it may be included in the continuity of care process, within the local network. It has different functional and organisational characteristics from an adult hospice. Personnel must have had dedicated PPC training, to ensure residential admissions, day-hospital and outpatient activities. 10.1016/j.jpainsymman.2021.12.031
Paediatric palliative care	"The active total care of the child's body, mind, and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres, and even in children's homes." https://www.iccp-portal.org/system/files/resources/Global_Atlas_of_Palliative_Care.pdf; *10.1007/s00482-008-0690-4*; https://iris.who.int/handle/10665/42001
Paediatric Palliative Care Team	A multi-disciplinary or inter-disciplinary team of professionals and other people who have received appropriate training. The members of the team will vary according to the needs of the child and family, as well as the available resources of the organisation/community. Members of the team can include, but are not restricted to, paediatricians, doctors, nurses, psychologists, social workers, counsellors, teachers, dieticians, physiotherapists, occupational therapists, child life specialists, play therapists, spiritual leaders, music and art therapists. Where resources allow, families are assigned a 'key worker' who ensures a coordinated and timely response to their needs. The child and the family are part of the team. https://icpcn.org/about-cpc/
Palliative chemotherapy	Treatments administered without curative intent, aiming to improve the patient's' quality of life. It can help slow the growth of the tumour and/or the proliferation of metastases and control some symptoms, but while causing more or less significant side effects, which must be balanced with a possibly (modestly) extended survival. Therefore, it is essential to explain this to the child and family, so they can make informed decisions in such delicate situations. 10.1016/S0140-6736(03)14433-9; 10.1001/jamaoncol.2015.2378; 10.1634/theoncologist.2017-0041
Palliative radiotherapy	Treatments administered without curative intent, aiming to improve the patient's' quality of life. This aims to reduce symptoms due to primary cancer or metastases, or to prevent their progression into symptomatic lesions, possibly prolonging survival. As it can cause side effects, it is essential to explain this to the child and family, so they can make informed decisions in such delicate situations. 10.21037/apm.2019.05.01; 10.1002/pbc.28292

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Palliative surgery	A procedure or intervention that aims to offer the best quality of life and maybe prolong survival. This includes interventions that can reduce the tumour mass, maintain organ function, or manage adverse events (e.g. bleeding, obstructions, effusions). It is crucial to inform patients and family members of possible unwanted consequences, the level of risk and morbidity, so they can make informed decisions in such delicate situations. 10.21037/apm-20-2370; 10.3332/ecancer.2022.1356
Proportionality of care	A treatment is "proportionate", and therefore legitimate and ethically permissible, if, in addition to being clinically appropriate, it is consciously accepted by the patient or, if no longer conscious, fits coherently into the person's life plan, however possible to rebuild it. Clinical appropriateness responds to the reasonable probability that the treatment, in that individual, can achieve the objective by positively modifying the prognosis and providing a reasonable prospect of recovery. Acceptance by the patient instead responds to his personal evaluation of the quality of the possible recovery, defined by the relationship between benefits and psycho-physical burdens that may derive from that treatment, even if clinically appropriate. As such, determining the proportionality of care belongs to the patient, while the doctor's role is to determine its appropriateness. This means that providing care to a child/adolescent and family must be based on an individualised cost/benefit assessment related to their overall quality of life. 10.1186/s12910-019-0353-2
Quality of life	The subjective perception of one's life in the socio-cultural context and in the context of the values belonging to the environment in which one lives and concerning one's needs, desires, worries, expectations and objectives. *https://www.who.int/tools/whoqol*
Terminal Care	Care for people who have a very short life expectancy, in the last weeks to days of life. The focus is on comfort, dignity, and symptom control, with an emphasis on psychosocial and spiritual support for patients and families. Recognizing that death is imminent, it aims to provide the best quality of life and avoidance of unnecessary interventions, withdrawing or withholding futile treatments, while supporting the family throughout the dying process. 10.1016/j.jpainsymman.2013.02.021
Therapeutic disproportion / persistence	A treatment with little or no probability of leading to an effect that the patient will perceive as a benefit, therefore, featuring an unfavourable cost-benefit ratio. The disproportion may concern the therapeutic and/or diagnostic approach, both for the healthcare team and the family members. Any inappropriate treatment must be stopped or not initiated, respecting the person's dignity and their family's values. On an ethical level, there is no difference between not initiating and suspending a disproportionate treatment. However, on an emotional or psychological level, these may lead to different effects, especially in situations when death can occur quickly following the suspension of treatment. https://pubmed.ncbi.nlm.nih.gov/28050241/