



Making Sense of Words: The Way to a Better Integration between Pediatric Oncology and Pediatric Palliative Care

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Pediatric Oncology (PO) & Pediatric Palliative Care (PPC)

Keypoints

widely accepted that the implementation of PPC in PO

- improves the quality of life of child and family
- helps reduce symptom burden
- diminishes costs of care and access to intensive care units at end of life
- makes dying at home more frequent

BUT

PPC is still poorly implemented in oncology practice
only 5% of pediatric oncologists and the child's family
discuss palliative advanced care planning

Friedrichsdorf 2015, Cuviallo 2020, Kaye 2021

Initiating Palliative Care Referrals in Pediatric Oncology

Andrea Cuviallo, MD, Jessica C. Raisanen, MSPH, Pamela K. Donohue, MS, ScD,
Lori Wiener, PhD, and Renee D. Boss, MD, MHS

**“How Can We Improve the Integration of PC Into
Pediatric Oncology?”**

Improving Communication

Interdisciplinary team communication

Hearing

Listening

Understanding

Colleagues



Pediatric Oncology

Pediatric palliative care

Problem

Lack of mutual unknowledge between the two disciplines with an unclear definition of

Language

Roles

Competences

3 Italian Scientific Society



Italian Association of
Pediatric Hemato-Oncology



Italian Society of
Palliative Care



Italian Society of
Pediatrics

Intersociety Commission



Pediatricians

Franca Benini
Lucia De Zen
Stefano Lijoi
Luca Manfredini
Marta Podda
Marco Zecca

12 components

Nurses

Andrea Mastria
Federico Pellegatta
Elena Rostagno
Francesca Uez

Psychologists

Roberto Capasso
Carlo Clerici

Method

- 6 online meetings from june 2021 to february 2022
- Identified FUNDAMENTAL WORDS for the DIALOGUE between pediatric oncology and pediatric palliative care
- Defined the MEANING by reviewing the literature and comparing expert's opinions.

Results

draft of a GLOSSARY with the definition of **28 words** also approved by all three societies boards published on each website and disclosed to all members (more than 12.000)

Chemioterapia palliativa	<p>Trattamenti la cui finalità non è curativa ma mirata a migliorare la qualità di vita dei pazienti. Il trattamento può contribuire a rallentare la crescita della massa tumorale e/o la proliferazione delle metastasi e aiutare a controllare alcuni sintomi. La chemioterapia palliativa può comportare effetti collaterali più o meno importanti a fronte di un prolungamento della vita modesto per cui è importante informare pazienti e i familiari delle possibili conseguenze indesiderate, affinché siano partecipi delle decisioni da prendere in una fase così delicata.</p> <p><i>-M Jefford, J Zalberg. Palliative chemotherapy: a clinical oxymoron. The Lancet 2003; 362 (9389):1082</i></p> <p><i>-HG Prigerson, Y Bao, MA Shah. Chemotherapy Use, Performance Status, and Quality of Life at the End of Life. JAMA .AMA Oncol. 2015;1(6):778J</i></p> <p><i>-Al Neughut, HG Prigerson. Curative, life-extending, and palliative chemotheraoy: new outcomes need new names. The Oncologist 2017;22:883-885</i></p>
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28 words

Advanced care planning

Bioethics

Child - Adolescent

Complex Needs

Eligibility criteria for PPC

End of life

Family members

Home care assistance

Incurability

Informed consent

Integrated care plan

Pain - Global pain

Palliative chemotherapy

Palliative radiotherapy

Palliative surgery

Pediatric Hospice

Pediatric palliative care

PPC Center

PPC network

Quality of life

Simultaneous care

Specialistic PPC team

Taking charge

Terminally ill patient

Therapeutic obstinancy

Conclusion

The definition of this glossary represents the basis on which to build the dialogue between PO and PPC for a complete approach to the pediatric patients affected by cancer.



Future steps

To pass from theory to practice
To integrate not only be nearby



