



# 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
- diminuishes 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, Cuviello 2020, Kaye 2021

#### Initiating Palliative Care Referrals in Pediatric Oncology

Andrea Cuviello, 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

#### **Pychologists**

Roberto Capasso Carlo Clerici

#### <u>Nurses</u>

Andrea Mastria Federico Pellegatta Elena Rostagno Francesca Uez

## 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)

<u> </u>	
Chemioterapia palliativa	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.
	-M Jefford, J Zalcberg. Palliative chemotherapy: a clinical oxymoron. The
	Lancet 2003; 362 (9389):1082
	-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
	-AI Neughut, HG Prigerson. Curative, life-extending, and palliative
	chemotheraoy: new outcomes need new names. The Oncologist 2017;22:883-
	885

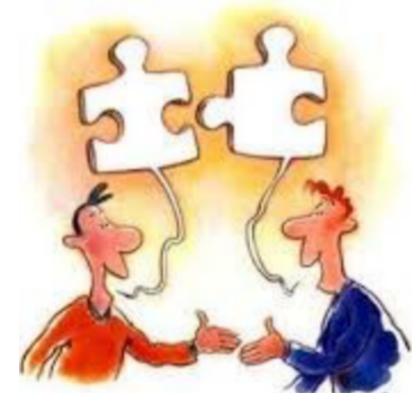
# 28 words

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

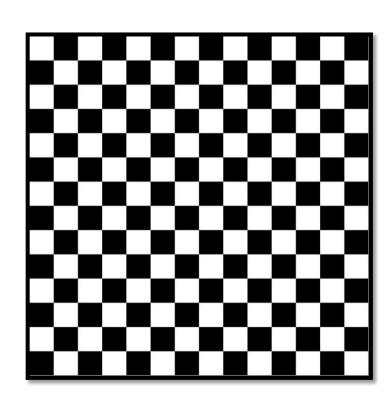
## Conclusion

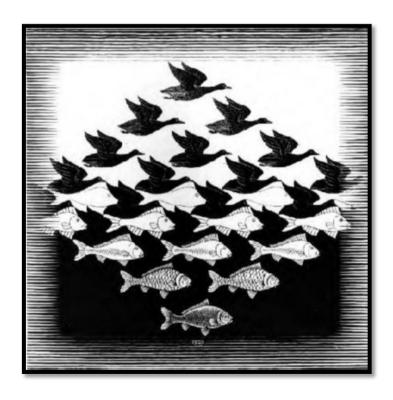
The definition of this glossary represents the basis on which to build the dialogue between PO and PPC for a complete approach to the pediatric patients affected by cancer.



# **Future steps**

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







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