

The vital role of Nursing Research and Education to Health Policy

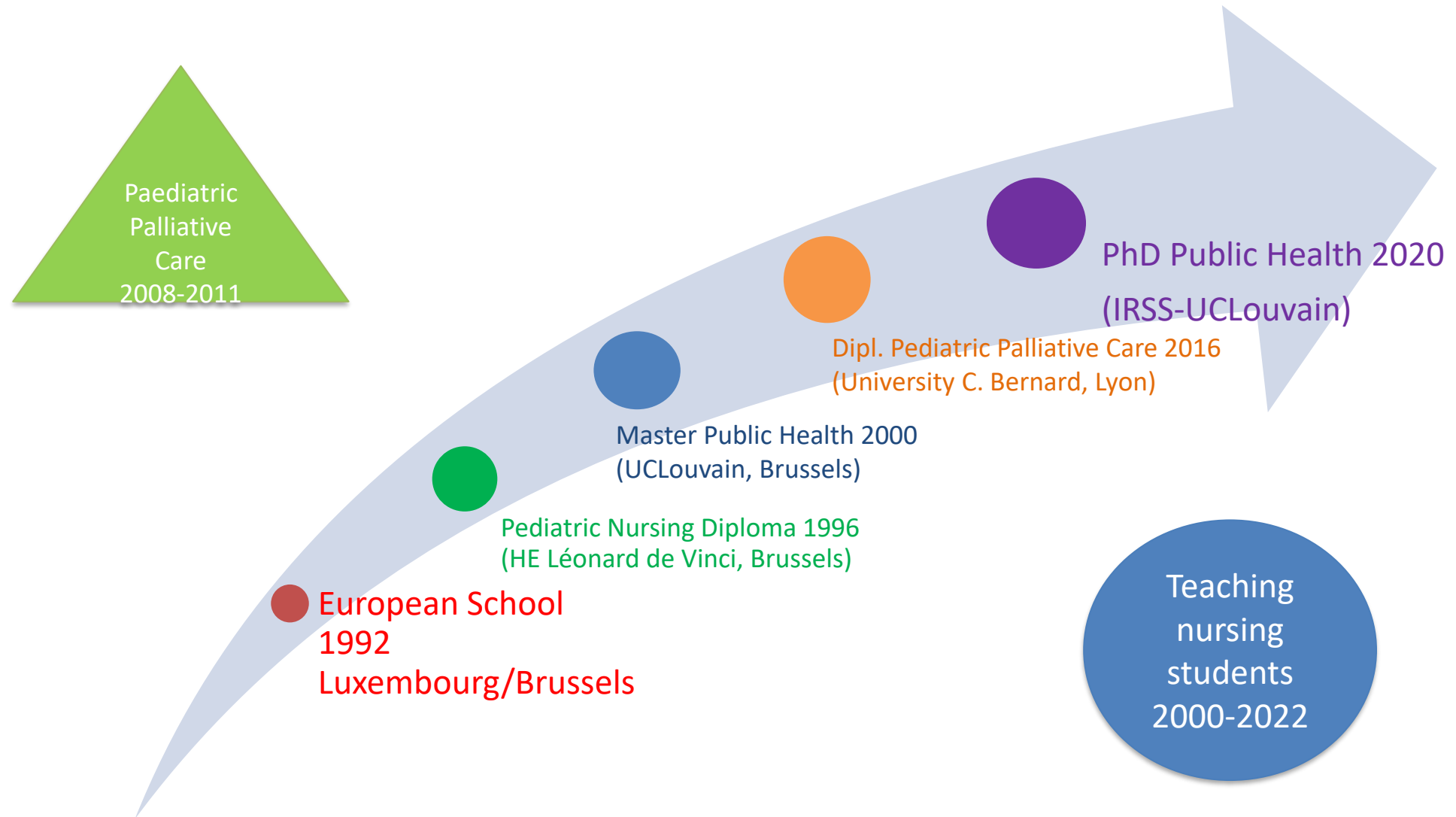
Prof. Dr. Marie Friedel
9th July 2024



NURSES AS TRAILBLAZERS AND PATHFINDERS: LET'S MAKE THINGS HAPPEN

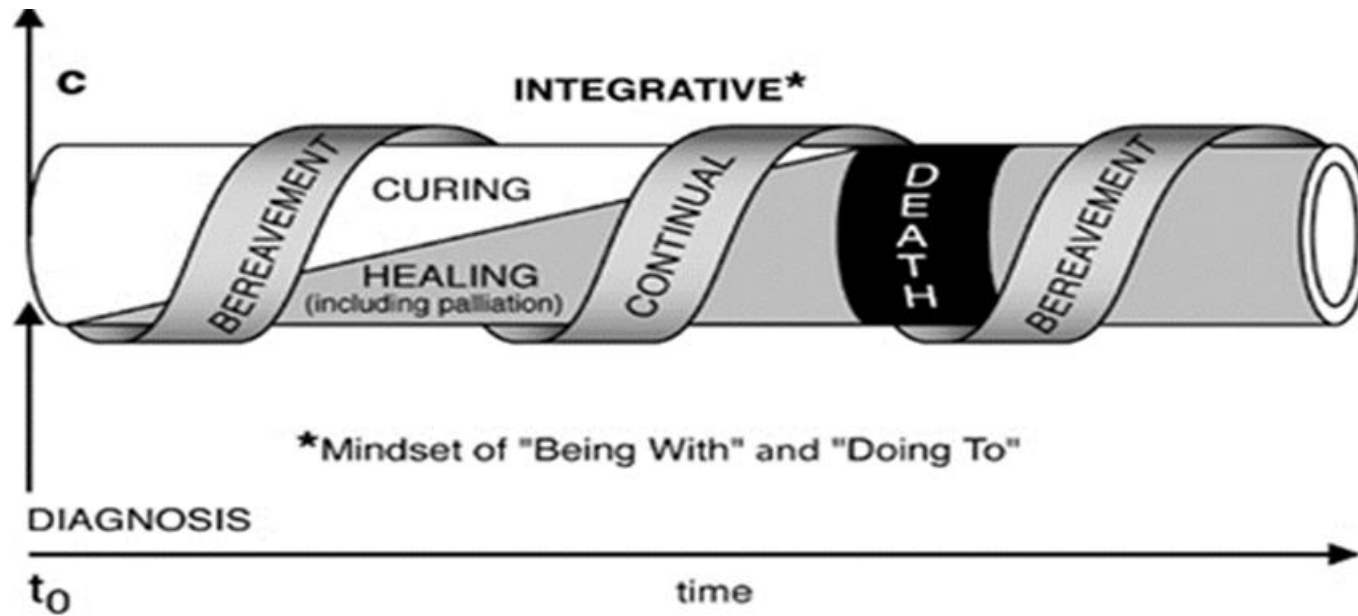


Professional and academic career



Belgian Pediatric Liaison Care Model

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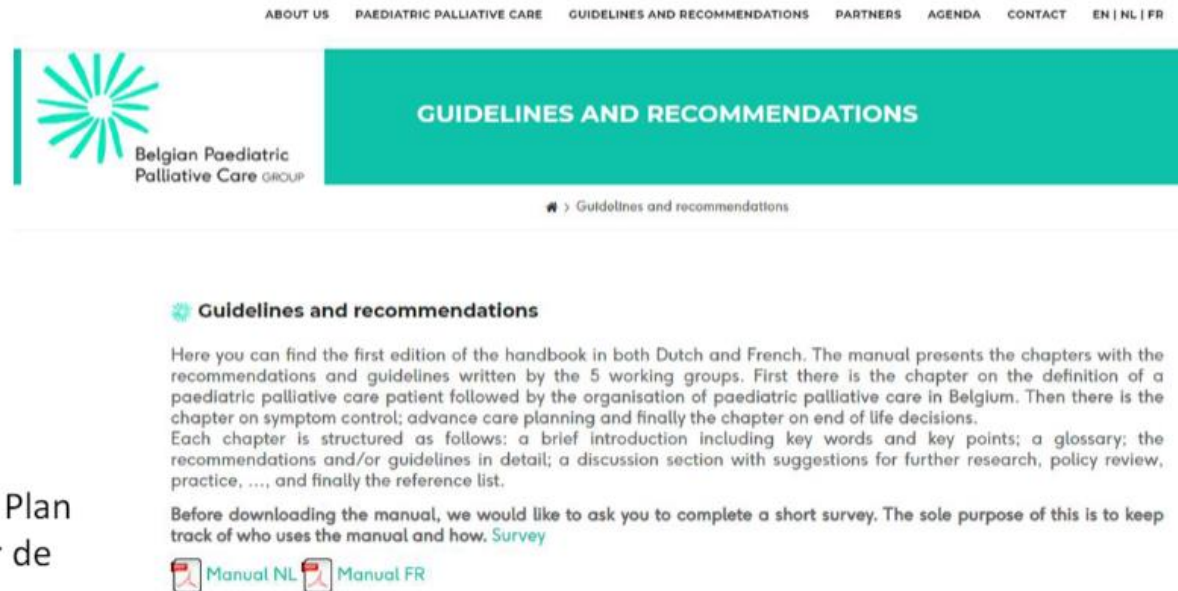
https://etaamb.openjustice.be/fr/arrete-royal-du-15-novembre-2010_n2010024459.html

Milstein J. A paradigm of integrative care.
Healing with curing throughout life in Journal of Perinatology, 2005.


Naissance du BBPC en 2012 et publication de guidelines en 2021

Belgian Pediatric
Palliative Care group
Dr M. Renard
(présidente)
www.bppc.be

Soutien par le SPF Santé publique
(partant de l'action 23 de l'ancien Plan
cancer) et par le Centre du cancer de
Sciensano pour le secrétariat
scientifique.



ABOUT US PAEDIATRIC PALLIATIVE CARE GUIDELINES AND RECOMMENDATIONS PARTNERS AGENDA CONTACT EN | NL | FR

 Belgian Paediatric
Palliative Care GROUP



GUIDELINES AND RECOMMENDATIONS

➤ > Guidelines and recommendations

Guidelines and recommendations

Here you can find the first edition of the handbook in both Dutch and French. The manual presents the chapters with the recommendations and guidelines written by the 5 working groups. First there is the chapter on the definition of a paediatric palliative care patient followed by the organisation of paediatric palliative care in Belgium. Then there is the chapter on symptom control; advance care planning and finally the chapter on end of life decisions. Each chapter is structured as follows: a brief introduction including key words and key points; a glossary; the recommendations and/or guidelines in detail; a discussion section with suggestions for further research, policy review, practice, ..., and finally the reference list.

Before downloading the manual, we would like to ask you to complete a short survey. The sole purpose of this is to keep track of who uses the manual and how. [Survey](#)

 Manual NL  Manual FR

Formation interdisciplinaire en soins palliatifs pédiatriques

Depuis 2012 Equipe de 20 formateurs-experts interréseaux
Formation axée sur les compétences-clés en SPP

En 2021



Convention relative à la formation intitulée *Les soins continus et palliatifs de la naissance à l'adolescence – Compétences-clés pour un accompagnement de qualité*

Article 1 - Partenaires

La présente convention est conclue entre :

- La Haute Ecole Léonard De Vinci (HE Vinci), représentée par sa Directrice-Présidente, Valérie Bievn, sa Directrice Académique, Geneviève Halleux, et le Responsable du Centre de Formation Continue, Sébastien Bar
- L'ASBL Formation en Algologie Pédiatrique et Soins continus (FAPS), représentée par sa Présidente, le Docteur Nadine Francotte, sa Trésorière, le Docteur Christine Devalck et sa Secrétaire, Madame Marion Faingnaert.



<https://www.vinci.be/fr/formations-continues/les-soins-continus-et-palliatifs-de-la-naissance-a-ladolescence-competences-clés-pour-un-accompagnement-de-qualite>

In 2014 First ICPCN Conference in Mumbai and Euthanasia law enlarged to minors in Belgium



Photo News

WHY?

2 years interuniversity degree in paediatric palliative care in Lyon/Paris (France)



Université Claude Bernard



Lyon 1

A PhD at Institute of Health and Society (IRSS-UC Louvain)

Participatory approach with all 5 Belgian liaison teams

Quality of life does not seem to be associated with the degree of or the burden of a disease, but rather on the quality of relations and on the support received and perceived.

The fundamental role of paediatric liaison teams is to create or restore those relations and links, across healthcare settings, time, and disease trajectories.



Photo credits: Marie Friedel

Métier à tisser à Aubusson

“Whatever you do, publish it!” Myra Bluebond-Langner

Friedel et al. *BMC Palliative Care* (2018) 17:77
<https://doi.org/10.1186/s12904-018-0324-2>

BMC Palliative Care

RESEARCH ARTICLE

Open Access



Building Bridges, Paediatric Palliative Care in Belgium: A secondary data analysis of annual paediatric liaison team reports from 2010 to 2014

Marie Friedel^{1,2*}, Bénédicte Brichard³, Christine Fonteyne⁴, Marleen Renard⁵, Jean-Paul Misson⁶, Els Vandecruys⁷, Corinne Tonon⁸, Françoise Verfaillie⁶, Georgette Hendrijckx⁴, Nathalie Andersson⁴, Ilse Ruysseveldt⁵, Katrien Moens⁹, Jean-Marie Degryse^{1,10} and Isabelle Aujoulat¹

Open access

Original research

BMJ
Paediatrics
Open

Access to paediatric palliative care in children and adolescents with complex chronic conditions: a retrospective hospital-based study in Brussels, Belgium

Marie Friedel^{1,2*}, Aurélie Gilson¹, Dominique Bouckenaere³, Bénédicte Brichard^{3,4}, Christine Fonteyne^{3,4}, Thomas Wojcik³, Etienne De Clercq¹, Alain Guillet⁶, Alaa Mahboub¹, Magali Lahaye^{1,7}, Isabelle Aujoulat^{1,8}

To cite: Friedel M, Gilson A, Bouckenaere D, et al. Access to paediatric palliative care in children and adolescents with complex chronic conditions: a retrospective hospital-based study in Brussels, Belgium. *BMJ Paediatrics Open* 2019;3:e000547. doi:10.1136/bmjpo-2019-000547

ABSTRACT

Background Paediatric complex chronic conditions (CCCs) are life-limiting conditions requiring paediatric palliative care, which, in Belgium, is provided through paediatric liaison teams (PLTs). Like the number of children and adolescents with these conditions in Belgium, their referral to PLTs is unknown.

Objectives The aim of the study was to identify, over a 5-year period (2010–2014), the number of children and adolescents with CCCs referred to PLTs.

What is known about the subject?

- The number of children and adolescents facing complex chronic conditions is increasing.
- Complex chronic conditions are considered life-limiting/life-threatening.
- A list of complex chronic conditions linked to International Classification of Diseases codes is available.

PEDIATRICS[®]

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Review Article

Instruments to Measure Outcomes in Pediatric Palliative Care: A Systematic Review

Marie Friedel, Isabelle Aujoulat, Anne-Catherine Dubois and Jean-Marie Degryse

Pediatrics January 2019, 143 (1) e20182379; DOI: <https://doi.org/10.1542/peds.2018-2379>

Journal of Palliative Medicine, Ahead of Print | Original Article

Face and Content Validity, Acceptability, and Feasibility of the Adapted Version of the Children's Palliative Outcome Scale: A Qualitative Pilot Study

Marie Friedel¹, Bénédicte Brichard, Sabine Boonen, Corinne Tonon, Brigitte De Terwangne, Dominique Bellis, Murielle Mevisse, Christine Fonteyne, Maud Jaspard, Marie Schruse, Richard Harding, Julia Downing, Eve Namisango, Jean-Marie Degryse, and Isabelle Aujoulat

Published Online: 15 Jul 2020 | <https://doi.org/10.1089/jpm.2019.0646>

The 22th April 2022, a call to invite me for an interview at university of Luxembourg



Sophie Lapierre and
Stéphane Pallage



Anne-Sophie Jung

He: “Would you like to be a Professor in nursing and implement 7 new bachelors and develop your research axes, here in Belval?”
Me: “How will it happen?”



Florence Nightingale, the lady with the lamp
<http://onedaycreative.com/lady-lamp-florence-nightingale>



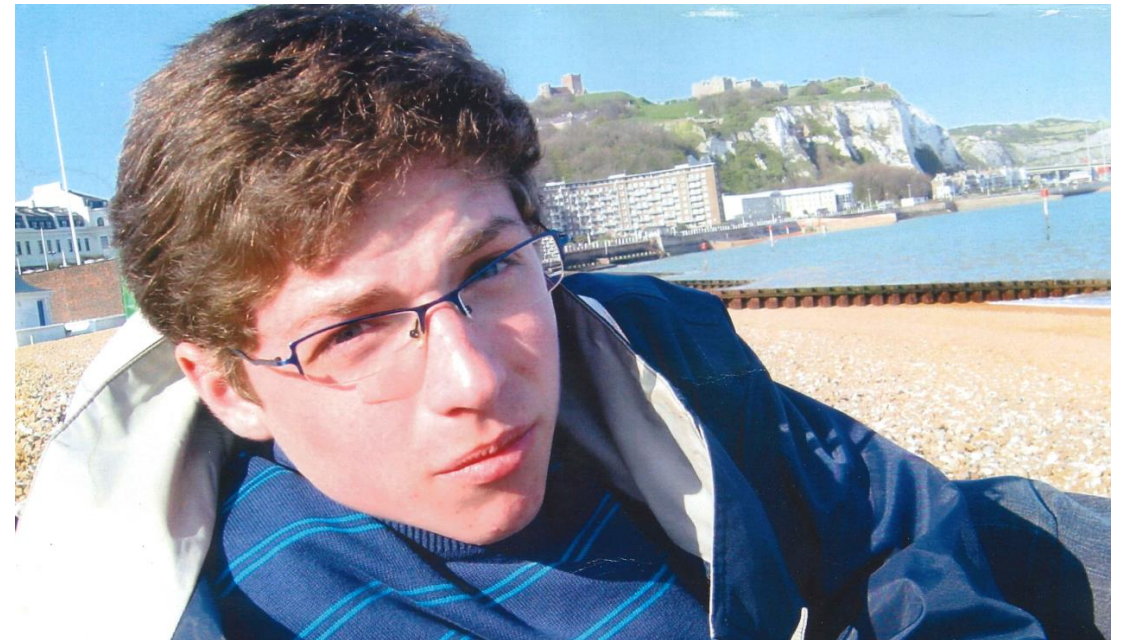
Source: <https://www.visitluxembourg.com/fr/adresse/museum/hauts-fourneaux-belval>

What did I learn from pediatric palliative care and how it helps me in my new position?

- **Quality of life** (WHO, 1998)
- **Temporality** (Carter 2016, Viallard 2004)
- **Complexity** (Morin 1993, Hamant, 2022)
- **Holistic approach** (Dossey 2015)
- **Vulnerability** (Zielinski 2020, Châtel 2018)
- **Uncertainty** (Hill et al 2020, Rutter et al. 2020, Senge, 2019)
- **Interdisciplinarity** (Tomczyk et al. 2021, Thiel et al. 2020)



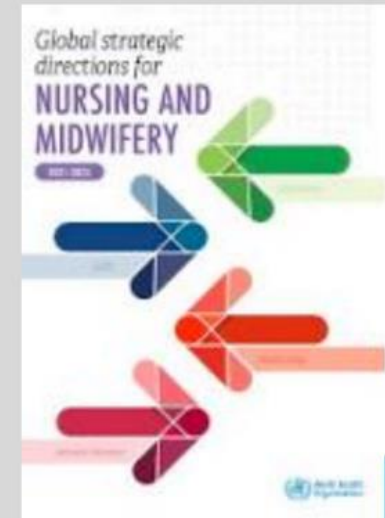
Little Boxes (Malvina Reynolds)



Luc Brilot. Photo used with permission of his parents

Emergency to address the nursing shortage


Evidence




THE LANCET

COMMENT | ONLINE FIRST

Urgent need to invest in health and care workers

Mathieu Boniol  · Amani Siyam · Khassoum Diallo · James Campbell

Published: May 23, 2022 · DOI: [https://doi.org/10.1016/S0140-6736\(22\)00576-1](https://doi.org/10.1016/S0140-6736(22)00576-1) ·  Check for updates



Nursing shortage amplified by the COVID - pandemic

6-10 millions nurses (WHO, 2020)

23-27 millions nurses and midwives (Lancet 2022)



[Au Brésil, ravagé par le Covid, des infirmières inventent une nouvelle «Main de Dieu» | Slate.fr](#)

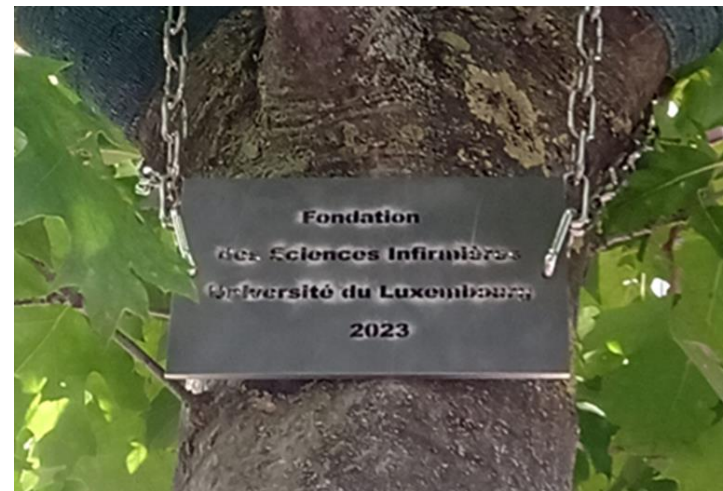
First Academic Day for our students, 18th September 2023



Photo credits: Aswin Lutchanah



Photo credits: uni.lu



Life is what happens while you are planning something else

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Painted stone seen at Omega 90, a palliative care house in Luxembourg



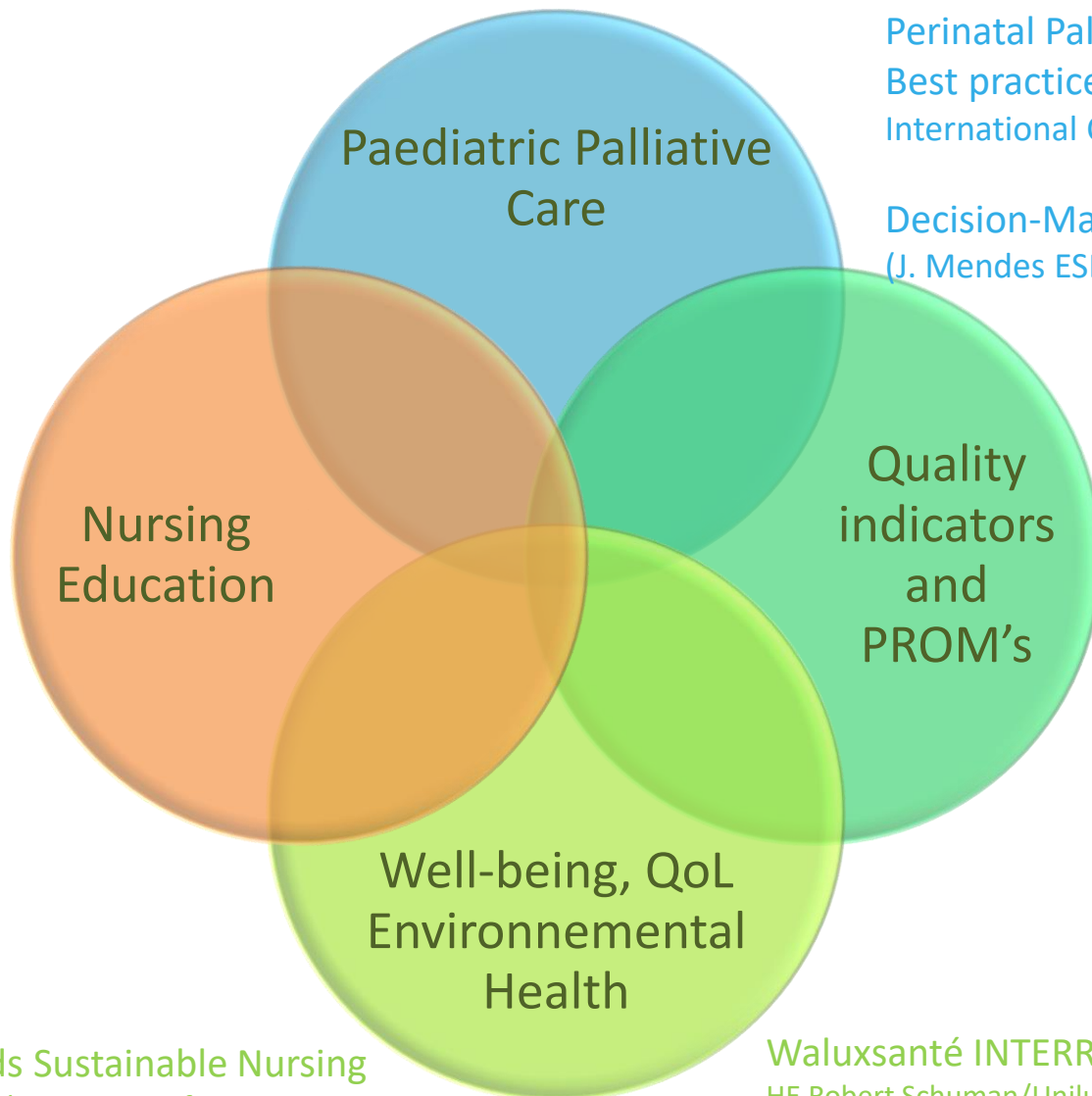
“The triple offer”
to invest in paediatric palliative care research

Research agenda Spiritual care
S. Buchter RESSPIR-Uclouvain

Spiritual care education
JC Servotte Hennalux
ERASMUS+

Curricula Pediatric Nursing
Pediatric Nursing Associations in Europe
(PNAE)

Towards Sustainable Nursing
Gaël Brulé CHANSE Norface



Perinatal Palliative Care
Best practice pain guidelines ICPCN
International Children's Palliative Care Network (ICPCN)

Decision-Making Processes
(J. Mendes ESEL, D. Garros University Alberta)

What matters most study.
Core indicator set in PPC
K. Widger University of Toronto
Funded by CIHR
and international research team

Waluxsanté INTERREG Econursing
HE Robert Schuman/Unilu

- 1. Paediatric Palliative Care Education
- 2. Paediatric Palliative Care Service
- 3. Paediatric Respite Care Service



First scientific conference on paediatric palliative care at unilu on 7th June 2024

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Take home messages



Listen to your inner voice
Embrace uncertainty and vulnerability
Don't go alone
Implement through advocacy and collaborations
Be patient
Celebrate every little success

Thank you !