Bioethics Medical Center
University of Basel

Monday 24th March 2025

# Is Euthanasia for children a compassionate response to address the complex suffering ? Bioethical strategy and shared decision-making tools.

Prof. Dr. Marie Friedel , RN, PhD Director of Programs in Nursing

UNIVERSITÉ DU LUXEMBOURG

# PLAN

1. Introduction
2. Development of Pediatric Palliative Care in Belgium
3. Decriminalization of child euthanasia in Belgium
4. Ethical aspects around compassion
5. Shared decision-making instruments to mitigate moral distress
6. Conclusions

# 1. INTRODUCTION

Parler de la mort aux enfants?

"Je voulais savoir à qui je pouvais me fier."

« Je n'aurais pas peur. Je veux voir le mort. »

« Est-ce qu'on me mettra dans le frigo? »

# Mutual pretense

Mutual pretense =
« Faux-semblants réciproques »

« The elephant is in the room »

Chacun sait qu'il y a la menace de la mort (éléphant), mais personne ne veut en parler, pour se protéger mutuellement.

=> FARDEAU majoré

Glaser & Strauss (1965) Awareness of dying

Bluebond-Langner M et al. (2005) Ethics and research with children

# A paradox between the perspective of death and the aim to promote quality of life

https://fotografiaprincipiantes.wordpress.com/category/contraste/

«Je veux vivre,
mais je vais mourir.»

Denis Vasse, Le poids du réel, la souffrance, Ed. du Seuil, 2008

# Find a balance?

Lyell Grünberg, slackliner

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# 2. DEVELOPMENT OF PEDIATRIC PALLIATIVE CARE IN BELGIUM

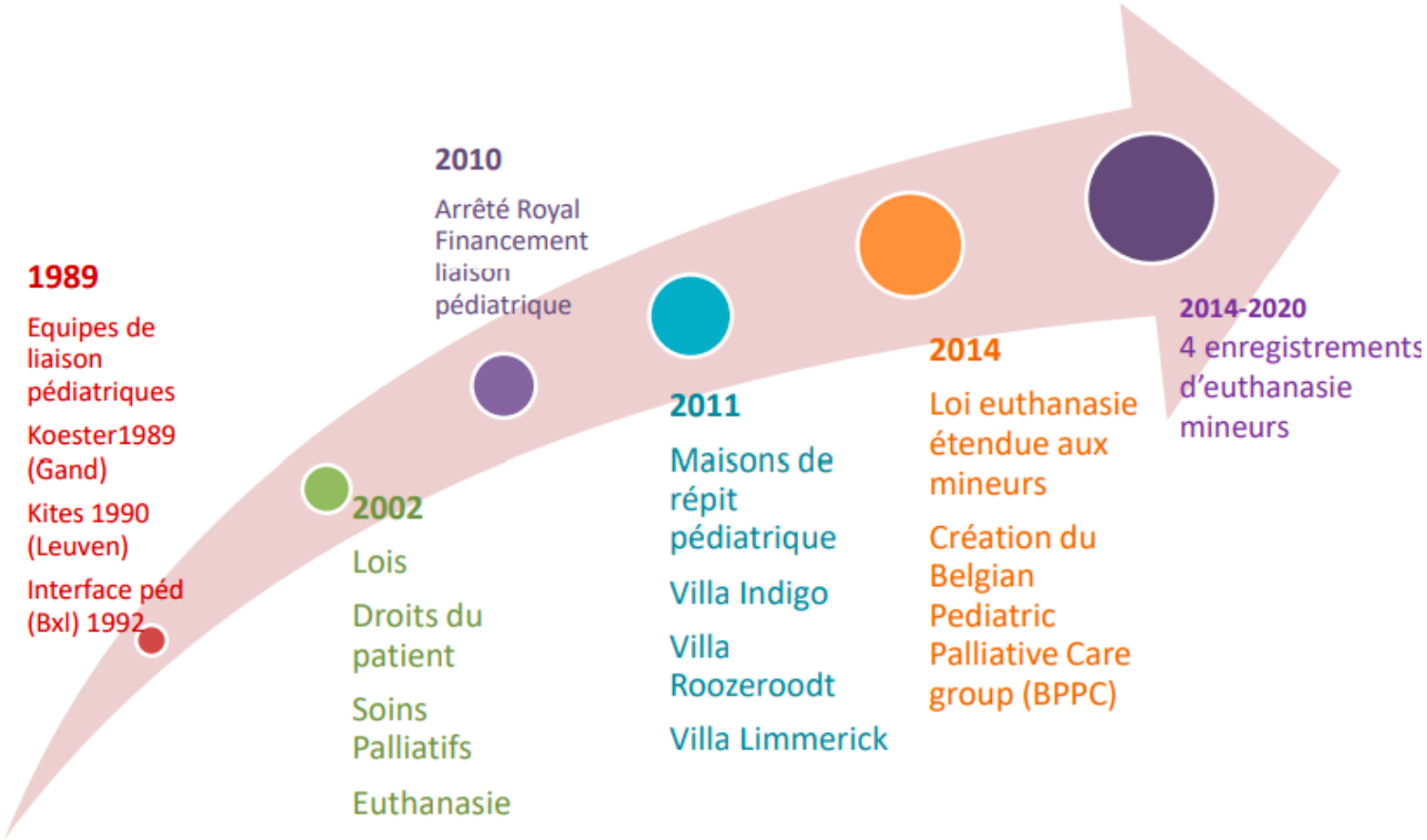



Fig. Marie Friedel (2021)

# Pediatric palliative care activities in Belgium (2010-2014)

- Sur base des rapports annuels des 5 équipes belges de liaison pédiatrique, transmis par le Plan Cancer (Ministère belge de la Santé Publique)
- 3607 enfants suivis sur 5 ans (2010-2014)
- 721 enfants/an en moyenne
- Durée de suivi était de 7 mois en moyenne
- 50% maladies oncologiques, 27% maladies neurogiques, 23% autres maladies
- 12% des enfants suivis sont décédés (n=428), la moitié d'entre eux (51%) à domicile.

Friedel M, Brichard B, Fonteyne C, Renard M, Misson JP, Vandecruys E, Tonon C, Verfaillie F, Hendrijckx G, Andersson N, Ruysseveldt I, Moens K, Degryse JM, Aujoulat I. Building Bridges, Paediatric Palliative Care in Belgium: A secondary data analysis of annual paediatric liaison team reports from 2010 to 2014. BMC Palliat Care. 2018 May 22;17(1):77. doi: 10.1186/s12904-018-0324-2.

- 2002: Three Laws : Patient rights, Euthanasia, Palliative Care
- 2014: Extension of Euthanasia Law to Minors
- 2016: Extended Definition of Palliative Care (not restricted to end of life stage)

# 3. DECRIMINALIZATION OF CHILD EUTHANASIA IN BELGIUM

Euthanasia, is defined in Belgium as:

- A medical act,
- that intentionnaly ends the life of a person,
- at his explicit request.

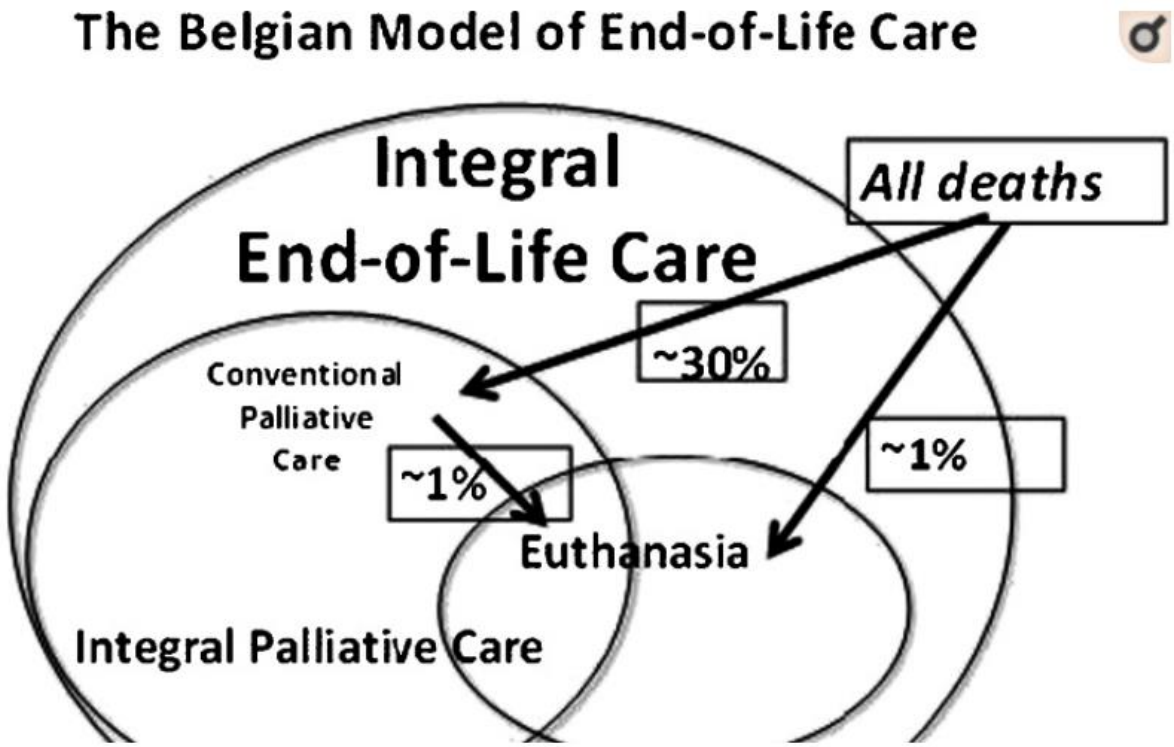
Loi belge dépénalisant l'euthanasie sous certaines conditions (2002)
https://www.ejustice.just.fgov.be/img_l/pdf/2002/05/28/2002009590_F.pdf

# Conditions
## (Belgian Law on euthanasia extended to minors13th February 2014)

- Terminal, incurable disease
- Unbearable constant physical pain
- Child's request
- Child must be conscious
- Child's capacity of discernment assessed by psychologist
- No age restriction
- Boths parents must agree
- Euthanasia is performed by physician
- Conscious clause

Dan, Fonteyne & de Cléty Lancet 2014

# Non-consensual Belgian Model of End-of Life Care




Bernheim JL, Distelmans W, Mullie A, Ashby MA. Questions and answers on the Belgian model of integral end-of-life care: experiment? Prototype? : "Eu-euthanasia": the close historical, and evidently synergistic, relationship between palliative care and euthanasia in Belgium: an interview with a doctor involved in the early development of both and two of his successors. J Bioeth Inq. 2014;11(4):507-29.

# 4. ETHICAL ASPECTS AROUND COMPASSION


Dessin: Pierre Kroll, 2014

# What is compassion?

- “Compassion is a virtuous response that seeks to address the suffering and needs of a person through relational understanding and action.”
(Sinclair et al. 2016)

ELSEVIER

Journal of Pain and Symptom Management

Volume 51, Issue 2, February 2016, Pages 193-203

Original Article

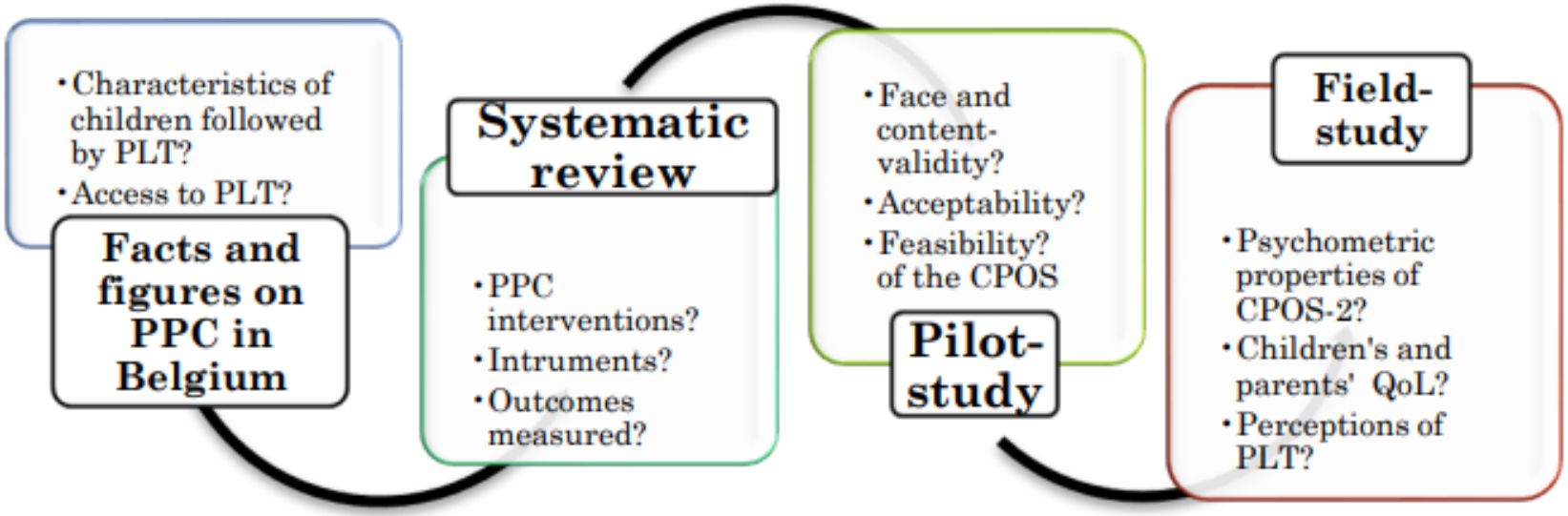
## Compassion in Health Care: An Empirical Model

Shane Sinclair PhD [a b], Susan McClement PhD [e], Shelley Raffin-Bouchal PhD [a], Thomas F. Hack PhD [e f], Neil A. Hagen MD, FRCPC [b c d], Shelagh McConnell PhD (C) [a f], Harvey Max Chochinov MD, PhD, FRCPC, FRSC [e g]

- During 20 years (1994-2014), not a single child request for euthanasia received by any of the 5 Belgian pediatric palliative care liaison teams. (Renard et al. 2017)
- 4 euthanasia enacted on minors between 2014 and 2021. Children were aged  9-16 years and suffered from Epidermolysis bullosis, Cystic fibrosis, Brain Cancer. Did they received palliative care? (Rapports annuels Commission fédérale de contrôle et d'évaluation de l'euthanasie)
- Funding of Palliative Care services remains the same since 2010 in Belgium. (Rapport annuel Plate-forme fédérale de l'évaluation des soins palliatifs)

# MOSAIK study

- Move to Open Shared Advanced Interventions for Kids with life-limiting conditions




Friedel M. 2016-2020 Recherche doctorale en santé publique. UCLouvain

# Sufficient access to pediatric palliative care services?

## PRÉSENTATION DE L'ÉTUDE IRSS UCL-FBSP

M. Friedel et Pr. I.Aujoulat

Photographie: Alexandre Mhiri

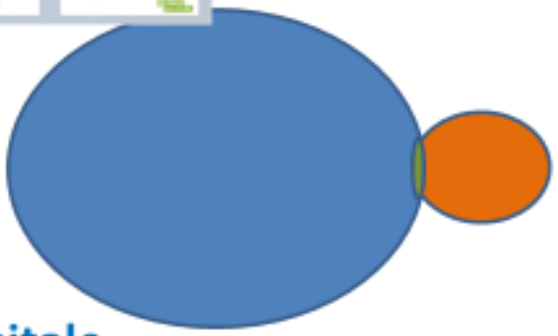
Parlement francophone bruxellois

## Résultats

**Total = 22721 enfants/adolescents atteints d'une maladie chronique complexe en région bruxelloise**

**22.533 hospitalisés dans un des 8 hôpitaux de la région Bxl capitale**

**572 suivis par une des 2 équipes liaison pédiatrique**



**384 hospitalisés et suivis par une équipe de liaison (soit 1,7%; n=384/22.533)**

Friedel M, et al. Access to paediatric palliative care in children and adolescents with complex chronic conditions: a retrospective hospital-based study in Brussels, Belgium. BMJ Paediatr Open. 2019 Sep 29;3(1):e000547.

palliabru

# Main results of the MOSAIK study

- Instruments to measure quality of life/quality of care not known and not used by teams. (Friedel et al. 2018)
- Quality of life score are not associated to degree of physical impairment of children (Friedel et al. 2023)
- Advanced care Planning:  to whom is it useful?
- What impacts most child's quality of life is the quality of relations/social support he perceives (Friedel et al. 2023)

*Palliative Care & Social Practice*

*Original Research*

# Focusing on life rather than illness: the lived experience of children with life-threatening and life-limiting conditions—a qualitative study

**Trine Brun Kittelsen, Charlotte Castor, Anja Lee, Lisbeth Gravdal Kvarme and Anette Winger**

*Palliative Care & Social Practice*

2024, Vol. 18: 1–17

DOI: 10.1177/26323524241301431

Bergstraesser et al. BMC Palliative Care 2013, 12:20
http://www.biomedcentral.com/1472-684X/12/20

BMC Palliative Care

RESEARCH ARTICLE Open Access

# The development of an instrument that can identify children with palliative care needs: the Paediatric Palliative Screening Scale (PaPaS Scale): a qualitative study approach

Eva Bergstraesser[1*], Richard D Hain[2] and José L Pereira[3]

**Abstract**

**Background:** The introduction of paediatric palliative care and referral to specialised teams still occurs late in the illness trajectory of children with life-limiting diseases. The aim of this ongoing multipart study was to develop a screening instrument for paediatricians that would improve the timely identification of children who could benefit from a palliative care approach.

**Methods:** We used a qualitative study approach with semi-structured interviews (Part 1) and a focus group discussion (Part 2) to define the domains and items of the screening instrument. Seven international paediatric palliative care experts from the UK, France, USA, and Canada took part in face-to-face interviews, and eleven paediatric health professionals from the University Children's Hospital, Zurich, participated in a subsequent focus group discussion.

**Results:** This preliminary phase of development and validation of the instrument revealed five domains relevant to identifying children with life-limiting diseases, who could benefit from palliative care: 1) trajectory of disease and impact on daily activities of the child; 2) expected outcome of disease-directed treatment and burden of treatment; 3) symptom and problem burden; 4) preferences of patient, parents or healthcare professional; and 5) estimated life expectancy. Where palliative care seems to be necessary, it would be introduced in a stepwise or graduated manner.

**Conclusions:** This study is a preliminary report of the development of an instrument to facilitate timely introduction of palliative care in the illness trajectory of a severely ill child. The instrument demonstrated early validity and was evaluated as being a valuable approach towards effective paediatric palliative care.

**Keywords:** Palliative care, Children, Family, Assessment, Needs

## Background

To be effective, paediatric palliative care (PPC) should be integrated into other aspects of paediatrics [1,2]. A number of studies [2-4] have clarified the needs of children and their families once the child's disease becomes incurable and progressive; they include symptom management, information, relationship with and access to health professionals, and participation in decision-making. PPC can address these; it is typically delivered through a shared care model, in which the PPC team works alongside primary attending professionals [1,5,6]. The effectiveness of this approach has been shown [6,7], but access to PPC is still limited in some first world countries, most notably in Switzerland. Recent reports [8-10] show that, despite WHO guidelines [11], referrals to palliative care are often made late in the trajectory of a life-limiting disease. This is true even in countries like the UK, where availability of palliative care for children is comparatively good [12-14]. Referral patterns remain less than ideal despite the availability of a number of scales designed to improve

* Correspondence: eva.bergstraesser@kispi.uzh.ch
[1]Department of Palliative Care and Oncology, University Children's Hospital Zurich, Steinwiesstrasse 75, CH-8032, Zurich, Switzerland
Full list of author information is available at the end of the article



Bergstraesser, Hain et al in BMC Palliative Care 2013, 12 (20)

# PaPas Scale

1. Evolution of the disease and its impact on daily activities
2. Expected result of treatment directed against disease
3. Intensity of symptoms and suffering
4. Patient preferences of family/health care professionnals
5. Estimation of  life expectancy

Score 0  to 40

If score 10-14: explain aim of PPC (Psycho-social support)

If score >15-24: start PPC (Symptom Control)

If score > 25: start specialized PPC (ACP, coordination of care)

# Qualitative study on PaPas Scale among pediatricians at Cliniques universitaires st Luc, Brussels, 2018

- Espérance de vie estimée (‘surprise question’)
- Impact de la maladie sur les activités quotidiennes (continuité suivi scolaire?)
- Impact du traitement sur qualité de vie
- Souffrance de l’enfant , des parents
- Complexité des soins/présence appareillages
- Degré de compréhension/d’acceptation de la situation par les parents

Matraka, Nora. *Critères d’identification des enfants nécessitant l’intervention de l’équipe de liaison en soins palliatifs pédiatriques selon les médecins des Cliniques Universitaires Saint-Luc : analyse qualitative et test d’un outil d’aide à la décision la Paediatric Palliative Screening Scale*. Faculté de santé publique, Université catholique de Louvain, 2018. Prom. : Aujoulat, Isabelle ; Friedel, Marie.

https://dial.uclouvain.be/memoire/ucl/object/thesis:15086

Chong et al. BMC Palliative Care (2020) 19:18
https://doi.org/10.1186/s12904-020-0524-4

BMC Palliative Care

RESEARCH ARTICLE Open Access

# Who needs and continues to need paediatric palliative care? An evaluation of utility and feasibility of the Paediatric Palliative Screening scale (PaPaS)

Poh Heng Chong[1*], Janice Soo[2], Zhi Zheng Yeo[1], Raymond Qishun Ang[1] and Celene Ting[1]

Song et al. BMC Palliative Care (2021) 20:73
https://doi.org/10.1186/s12904-021-00765-8

BMC Palliative Care

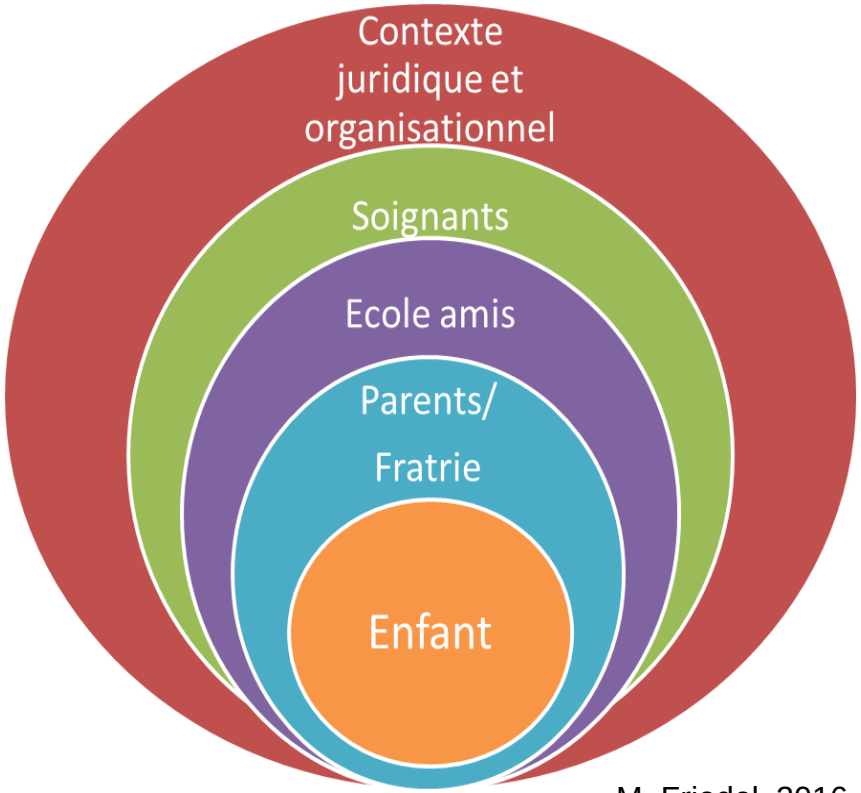
RESEARCH Open Access

# Paediatric palliative screening scale as a useful tool for clinicians' assessment of palliative care needs of pediatric patients: a retrospective cohort study

- Child as agent: How can we hear his voice? Which autonomy in a family-centred, systemic approach?

- How can we evaluate child's capacity in absence of a validated intrument?

  *Comprehension
  *Appreciation
  *Decision
  *Reasoning (Dorscheidt 2023)




M. Friedel, 2016

# The concept of relational autonomy

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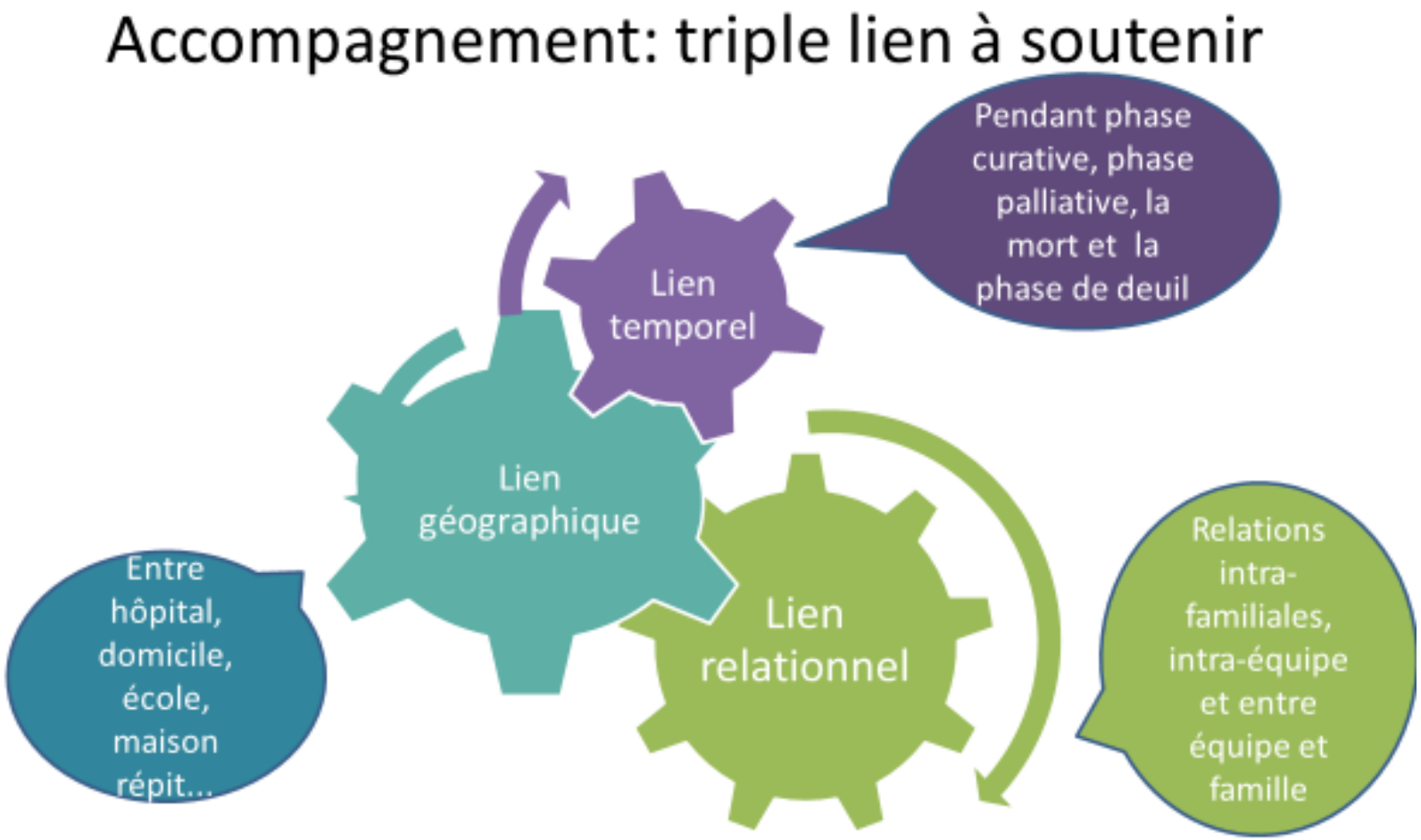
**RELATIONAL AUTONOMY: MOVING BEYOND THE LIMITS OF ISOLATED INDIVIDUALISM,**
WALTER & ROSS PAEDIATRICS, 2014

| Variable | In-control Agent Autonomy | Relational Autonomy |
|---|---|---|
| Reasons for decisions | Rational reasons | Rational/emotional reasons |
| Who is the decision-maker | Patient's surrogate | Surrogate can rely on those they trust |
| Adolescent participation in decision-making | Limited | Respect the voice of adolescents |
| Adolescent participation in EOL decision-making | Participation not taken into account | Respect the voice of adolescents |
| Role of provider | Provides medical expertise | Provides medical expertise, engages in the emotional experience of the patient |
| Influence of others on the patient | Limited, to be avoided | Expected |
| Information given to the adolescent | Depends on patients' decision-making capacity | Depends on patients' decision-making capacity and parents' wishes |

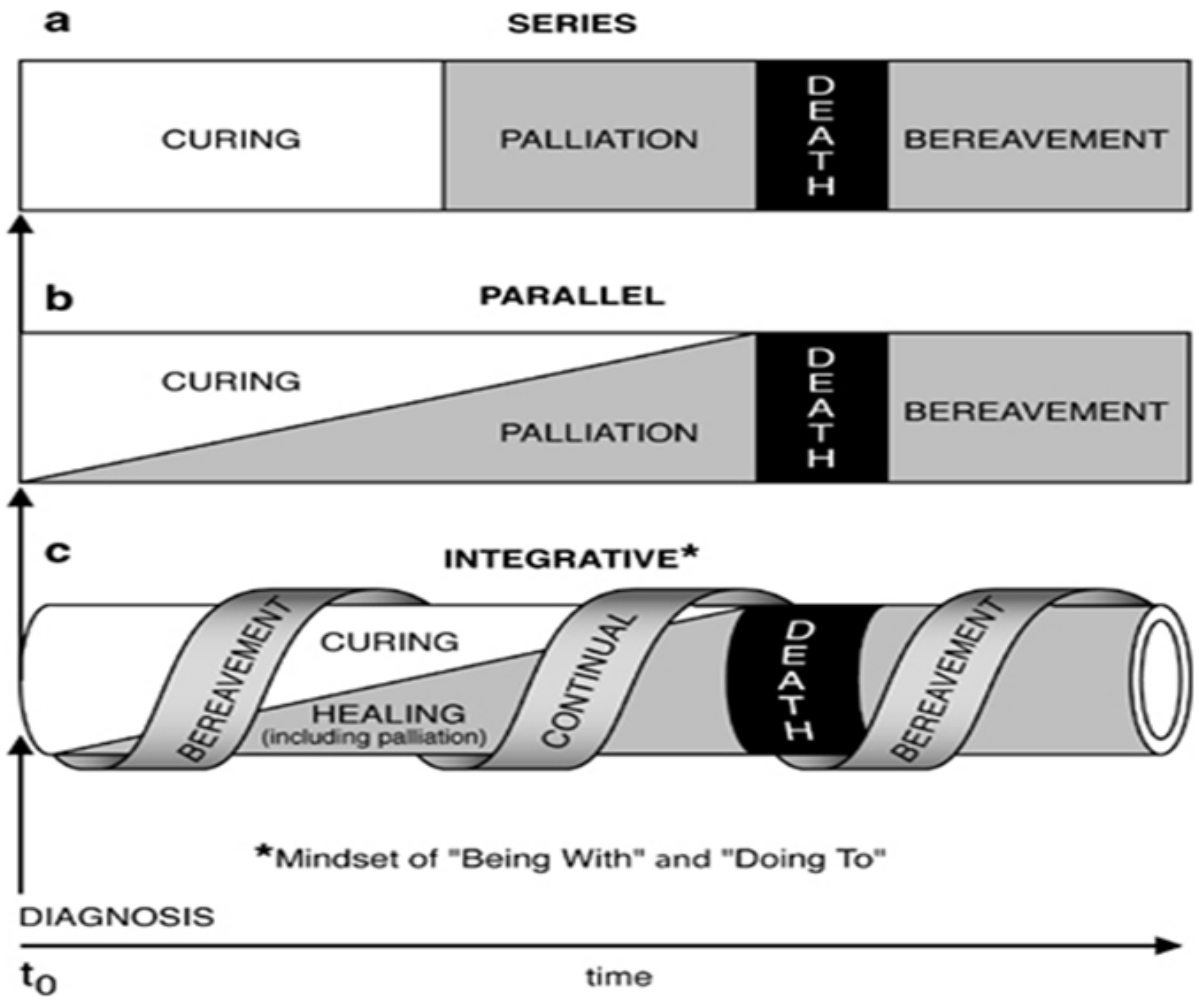
30

Walter, J. K., & Ross, L. F. (2014). Relational autonomy: moving beyond the limits of isolated individualism. Pediatrics, 133 Suppl 1, S16–S23.

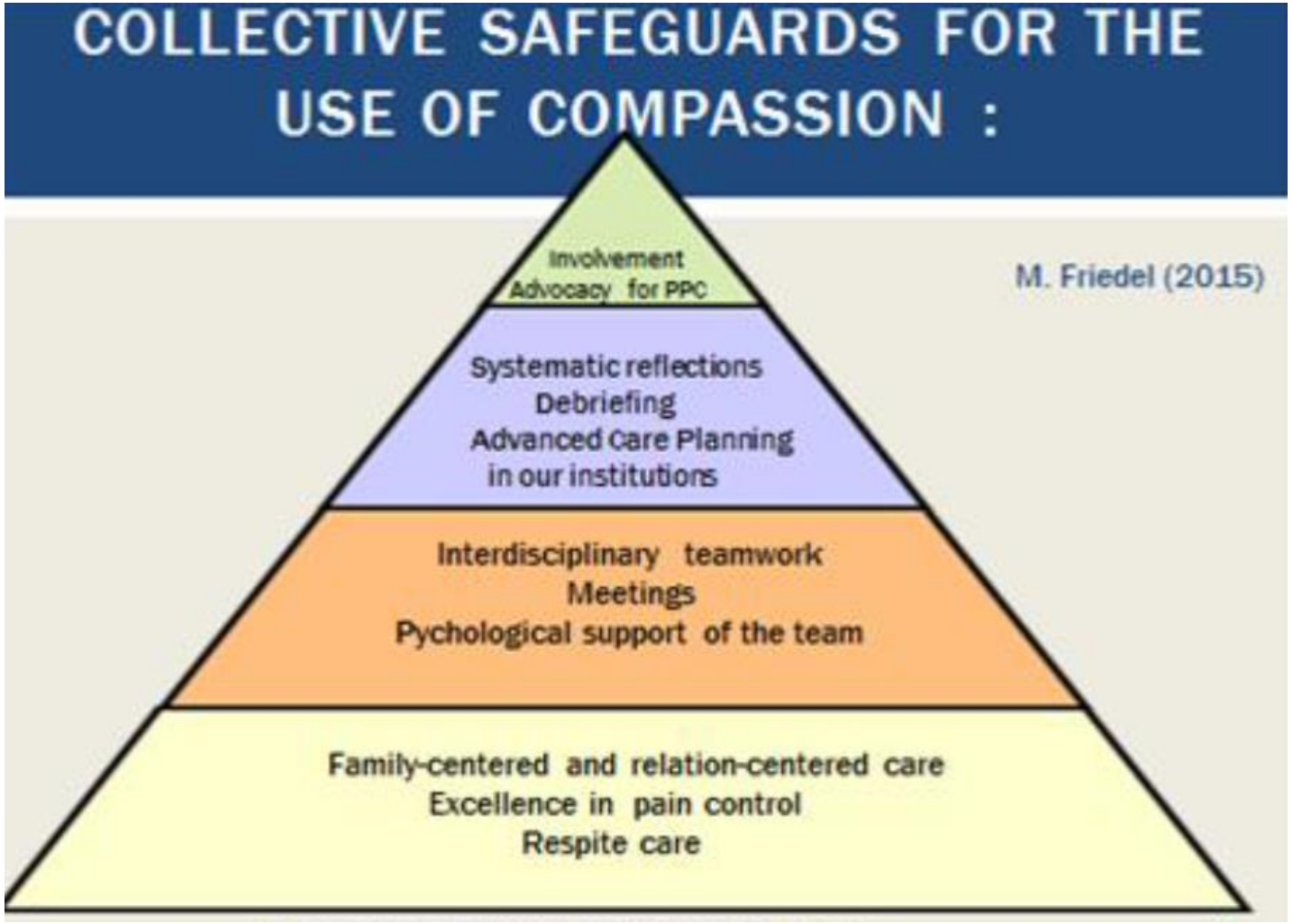
# The role of liaison nurses




Friedel M. D'un passage à l'autre. Quelles analogies entre la vie et la mort? Soins Ped Pueric 2015;37(289):37-41




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


COLLECTIVE SAFEGUARDS FOR THE USE OF COMPASSION :
Involvement
Advocacy for PPC
M. Friedel (2015)
Systematic reflections
Debriefing
Advanced Care Planning
in our institutions
Interdisciplinary teamwork
Meetings
Pychological support of the team
Family-centered and relation-centered care
Excellence in pain control
Respite care

# 5. SHARED DECISION-MAKING INSTRUMENTS TO MITIGATE MORAL DISTRESS

- Four steps decision-making approach (Bolly & Grandjean, 2004)
- Tool to help complex decision-making (Chénard, 2022)
- Game theory and PPC (Friedel & Pallage, 2023, 2024)

# Four-step decision-making approach

GIRAFE
Groupe Interprofessionnel de Recherche, d'Aide à la décision et de Formation en Ethique clinique


This approach comprises four separate stages during which the discussion leader encourages dialogue between the care providers.

1. Listening to what is said focuses on the specifics of each situation that is part of the background of a patient and their close relatives.
2. Being receptive to emotions and judgement is where care providers are invited to consider and be aware of their personal experiences before moving on to a discussion phase.
3. Taking a step back is based on a seven-step grid. It allows the values in play to be put into context and the reference points from various disciplines to be incorporated.
4. Sharing in the change works via the creative abilities that anyone an develop to create their future and the balance between 'giving' and 'receiving' as discussed in relationship ethics.

| | | | |
|---|---|---|---|
| 1. Putting into writing the individual's decision, spontaneous | | | |
| 2. Creation of three scenarios (in small groups) | **Scenario 1** | **Scenario 2** | **Scenario 3** |
| **3. Analysis**<br>A. Consequences for:<br>- The patient<br>- Their close relatives<br>- The team<br>- Society<br>B. - Preferential values<br>- Values neglected<br>- Priority values<br>C. Resources required for implementation | | | |
| 4. Setting out the main ethical issue(s) | | | |

Source: Bolly & Grandjean, RESSORT (2004)

https://ressort.hers.be/images/ressources/Four-stepdecision-makingapproach.pdf

## 1
## La décision et son contexte

Quelle décision dois-je prendre ? _____

_____

_____

Pour quelles raisons dois-je prendre cette décision ? _____

_____

_____

Quelles sont mes craintes par rapport à cette décision ? _____

_____

_____

Est-ce une décision sur laquelle je ne pourrai pas revenir en arrière ? ☐ Oui ☐ Non

De combien de temps est-ce que je dispose pour la prendre _____

- Chénard (2022) https://phare-education.com/wp-content/uploads/2020/09/2020_Outil_aide_decision_complexe.pdf

# Game theory and pediatric palliative care

MÉDECINE PALLIATIVE

## "The day my son dies, I will die, too." Shared decision-making through game theory in paediatric palliative care: A clinical case scenario - 08/05/24

*« Le jour où mon fils meurt, je vais mourir aussi.» Les processus décisionnels partagés en soins palliatifs pédiatriques basés sur la théorie des jeux : une étude de cas*

Doi : 10.1016/j.medpal.2024.04.004

Marie Friedel [a,*], Stéphane Pallage [b]

[a] Department of Life Sciences and Medicine (DLSM), Faculty of Life Sciences, Technology and Medicine (FSTM), University of Luxembourg, Esch-sur-Alzette, Luxembourg

[b] Université du Québec à Montréal (UQAM), Montréal, Canada

*Corresponding author at: Department of Life Sciences and Medicine, University of Luxembourg, 2, avenue de l'Université, 4365 Esch-sur-Alzette, Luxembourg.Department of Life Sciences and Medicine, University of Luxembourg2, avenue de l'UniversitéEsch-sur-Alzette4365Luxembourg

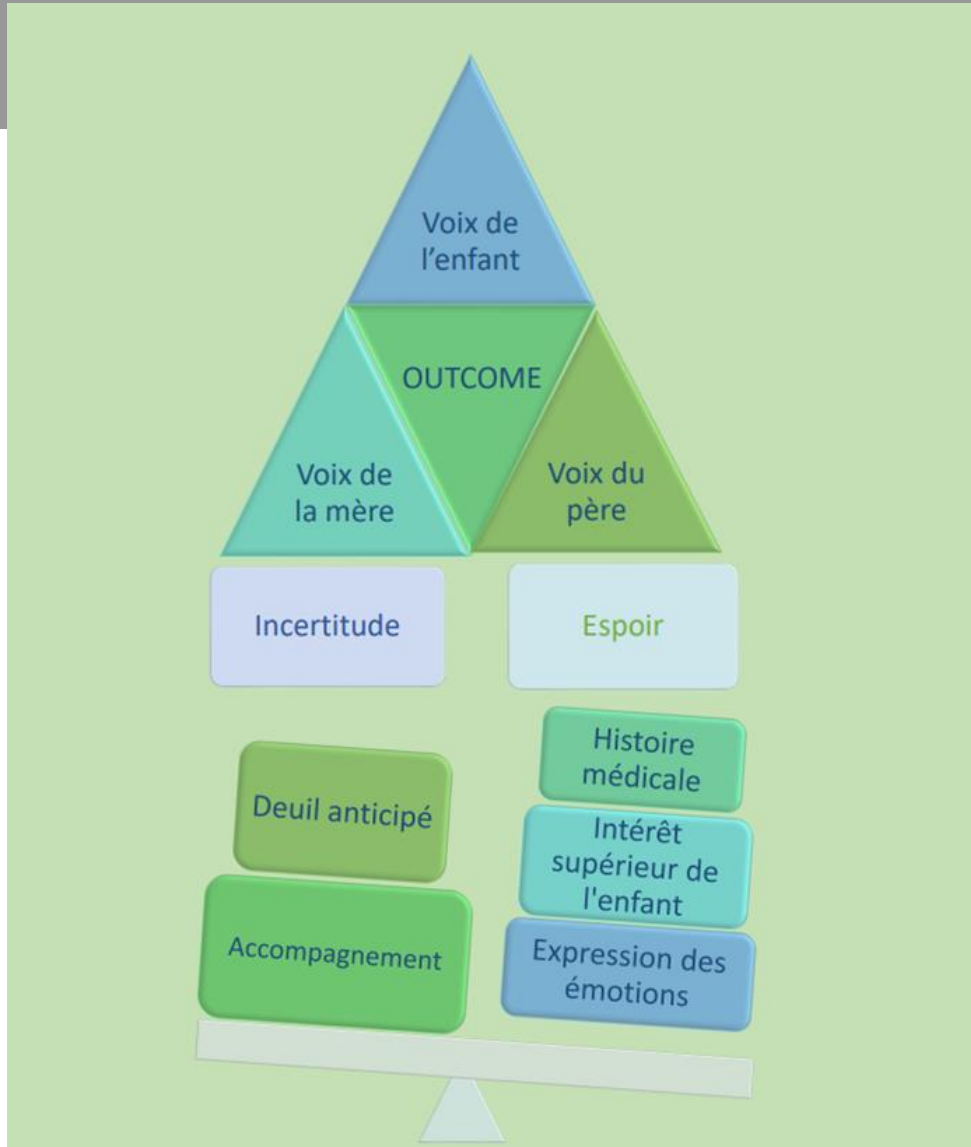
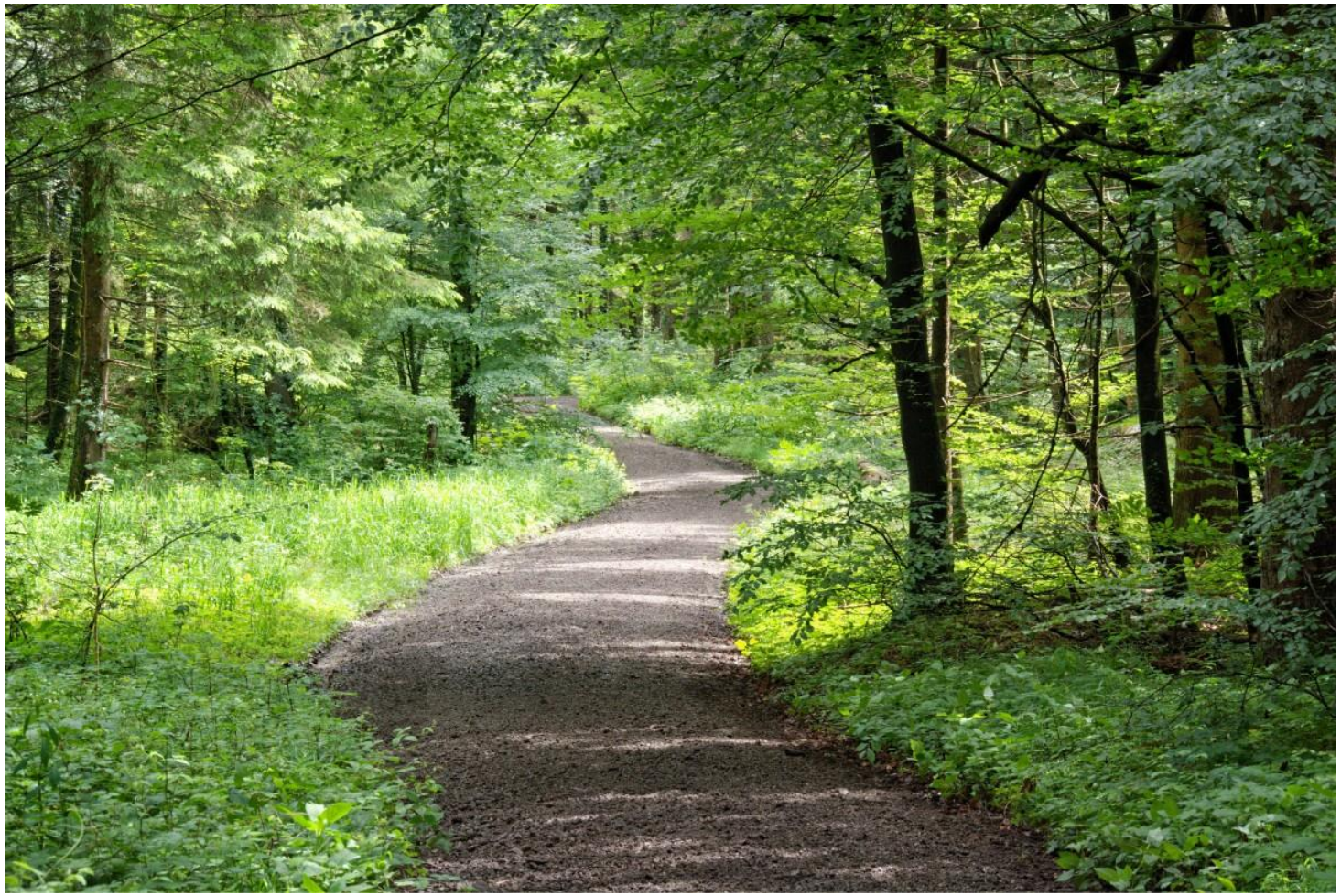



Fig. 1 Recherche de *l'Equilibrium* dans les processus décisionnels partagés selon la théorie des jeux (Friedel & Pallage 2023)

# 6. CONCLUSIONS



- How can we evaluate child's capacity of discernement? (Dorscheidt 2023)
- How to address and accompany moral distress and vicarious traumatism of parents and health carers? (Semler 2023, Han et al. 2023, Krick et al. 2020, Sarro et al. 2022)
- Proportionality of care taken into account complexity? (Morin, Beauchamps & Childress)
- Place left to shared-decision making? (Friedel & Pallage 2024, Hain et al. 2022, Chenard 2022)
- Impact of a euthanasia law on child, family, society and grieving process? (Andriessen et al. 2020, Goldberg et al. 2021)

- Individual situation versus legal standardization?
- Access to pain management, pediatric palliative care services, respite care and financial constraints?
- Needs inventories among children and their families?

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# Right of the dying child

## Charte de Trieste

Benini F, Vecchi R, Orzalesi M (2014) A charter for the rights of the dying child, The Lancet, 383 (9928)
Benini et al. (2017) the rights of the dying child and the duties of healthcare providers: the Trieste Charter Tumori, 103(1)

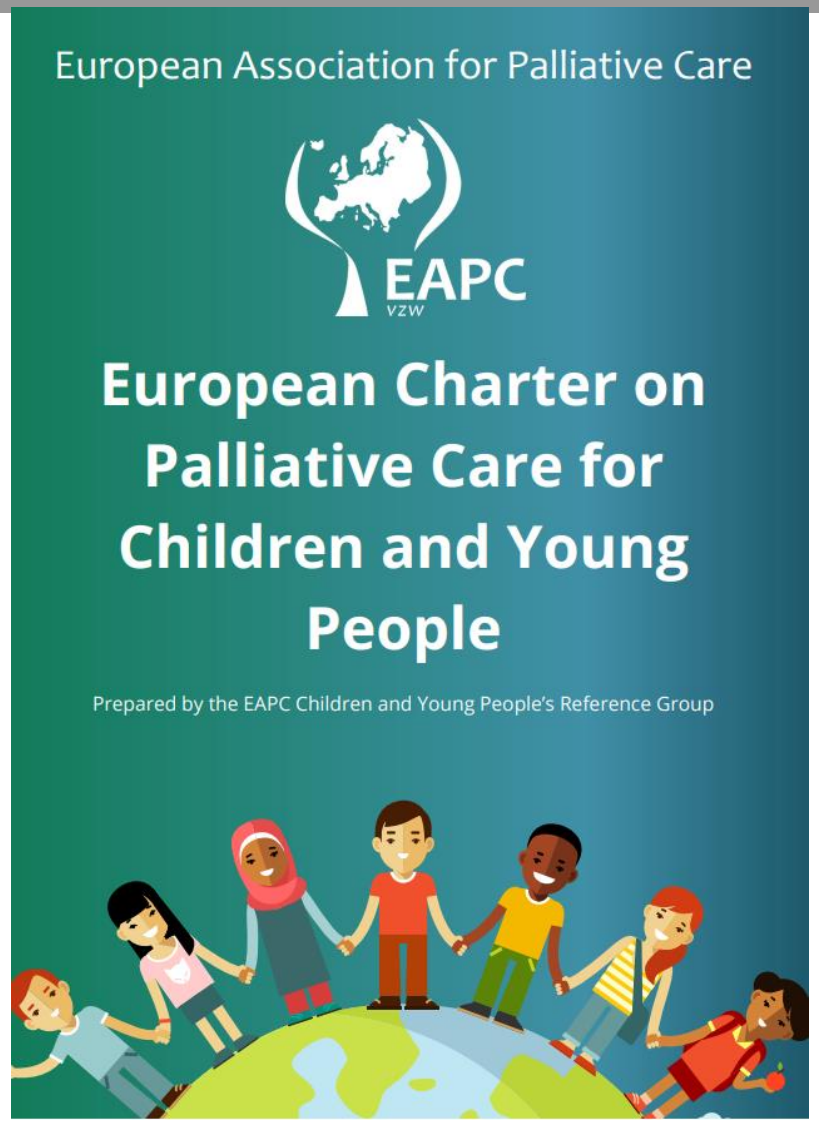
1. Droit d'être considéré comme une personne jusqu'à la mort, quel que soit l'âge, le lieu, la maladie et le contexte de soins.
2. Droit de recevoir un traitement efficace contre la douleur ou tout autre symptôme physique et psychologique induisant des souffrances, au travers de soins qualifiés, cohérents et continus.
3. Droit d'être entendu et d'être informé correctement au sujet de sa maladie en tenant compte de ses désirs, de son âge et de sa capacité à comprendre.
4. Droit de participer, en fonction de ses capacités, de ses valeurs, de ses désirs aux plans de soins /aux décisions de soins concernant sa vie, sa maladie et la mort.
5. Droit d'exprimer et dans la mesure du possible voir ses sentiments, désirs et ses attentes pris en considération.

# Droit aux soins palliatifs pédiatriques

6. Droit de voir ses croyances culturelles, spirituelles et religieuses respectées et de recevoir un accompagnement spirituel en accord avec ses souhaits et ses choix.
7. Droit d'avoir une vie sociale et relationnelle adaptée à son âge, sa maladie et ses attentes.
8. Droit d'être entouré par les membres de sa famille et tous les êtres aimés qui sont soutenus adéquatement et protégés des conséquences de la maladie de l'enfant.
9. Droit d'être soigné dans un lieu adapté à son âge, ses besoins, ses désirs et qui permet la proximité avec sa famille.
10. Droit d'avoir accès à un programme spécifique de soins palliatifs pédiatriques qui évite des pratiques de soins futiles ainsi que l'abandon thérapeutique.

Charte de Trieste téléchargeable en français à l'adresse:
www.fondazionemaruzza.org/wp/wp-content/uploads/2017/05/CARTA-TRIESTE_FRANCESE.pdf

# A European charter

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« Expect the best,
Prepare for the worst,
Be ready for surprises!»

marie.friedel@uni.lu

UNIVERSITÉ DU LUXEMBOURG