

Creating a safe environment for children and parents:  
How the **concept of holding**,  
applied to paediatric palliative care (PPC),  
might collide with the Belgian child euthanasia procedure?

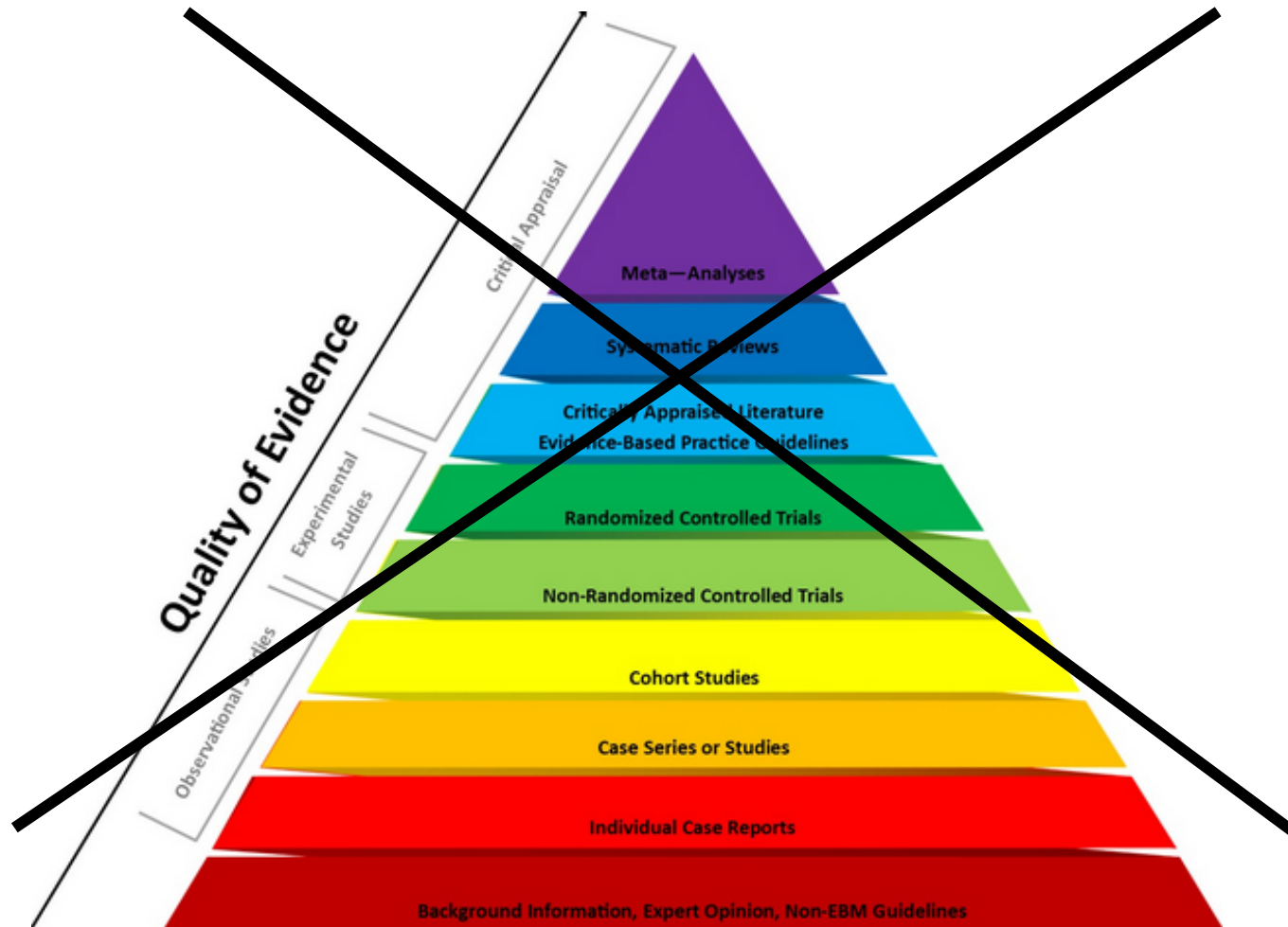
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# 1.Objectives

- to present analogies which can be found between the holding concept developed by Winnicot and the family-centered holistic approach in PPC
- to demonstrate how the holding concept might collide with the procedure of the Belgian euthanasia law extended to minors

We won't present the results of a randomized clinical trial



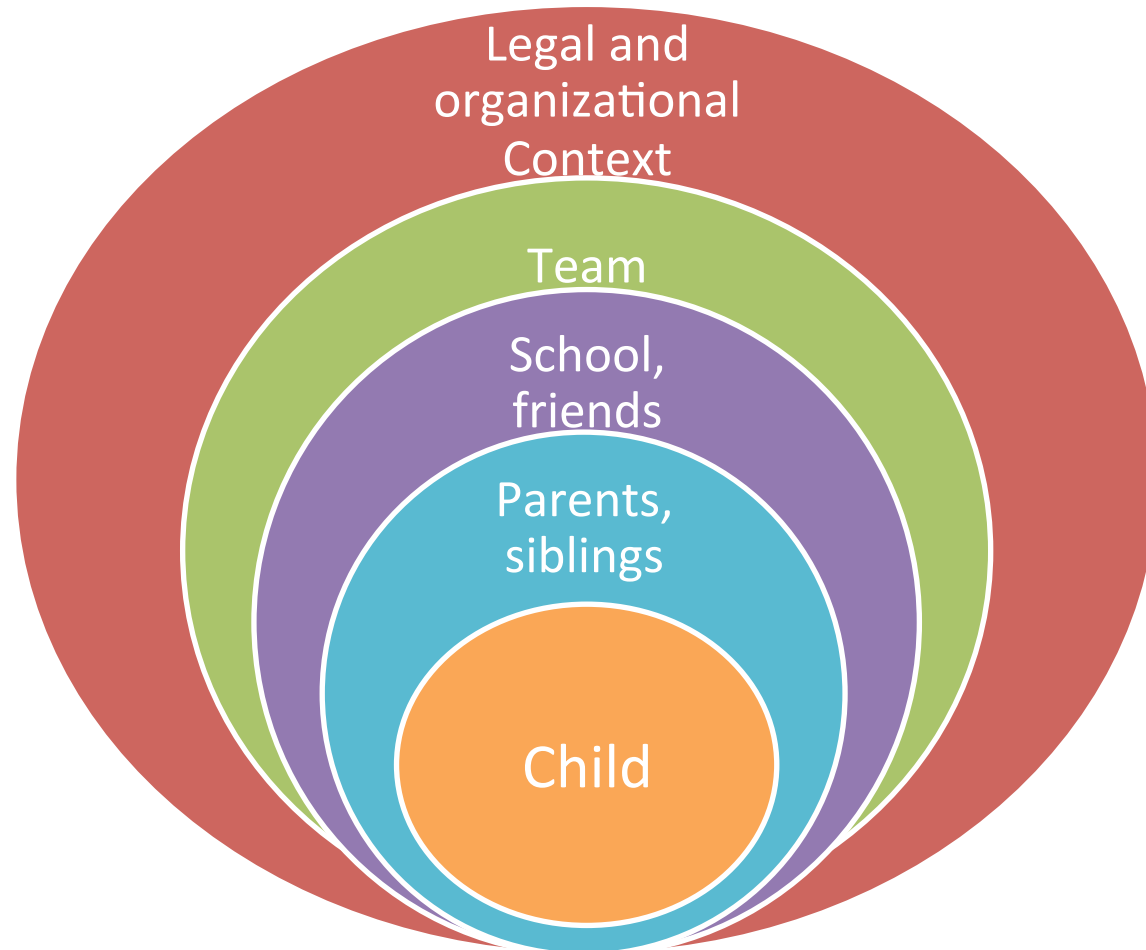
## 2. The holding concept

- Secure environment Winnicott 1972
- Secure model of care Marin & Worms 2015
- Attention to infant's verbal and non verbal signs results in a meaning making process: « Process of intime transformation, which allows unthinkable emotions and sensations to be thinkable, in order to be hold/ contained in a thought, instead of being evacuated in an act or derivated in somatic attacks.» Didier Houzel, 1987 cited by Gaucher-Hamoudi 2007
- Reliability and dependance are the core element of care Winnicott, 1970
- No hierarchy between patients and carers Winnicott 1970

- Pallium (latin) means blanket
- Sense of protection
- Substitution of blankets into ... hats!

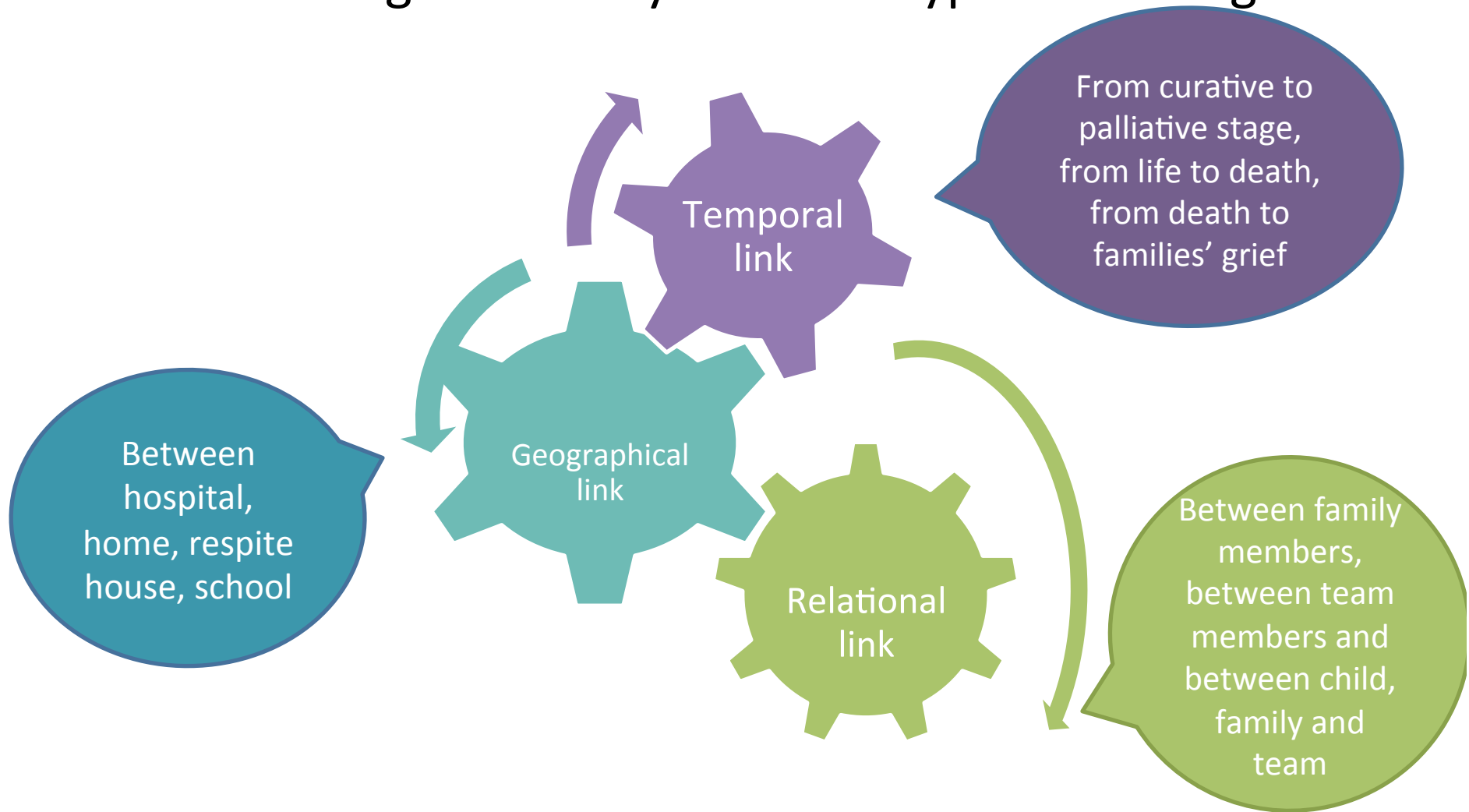


# Child is embedded in a family, holded?



# Paediatric Liaison Care Model:

is ensuring continuity of care a type of holding?



# 3. The Belgian law on euthanasia

Definition of euthanasia:

Procedure realized by a physician

who deliberately terminates the life of a person

at the request of this person



# Historical steps

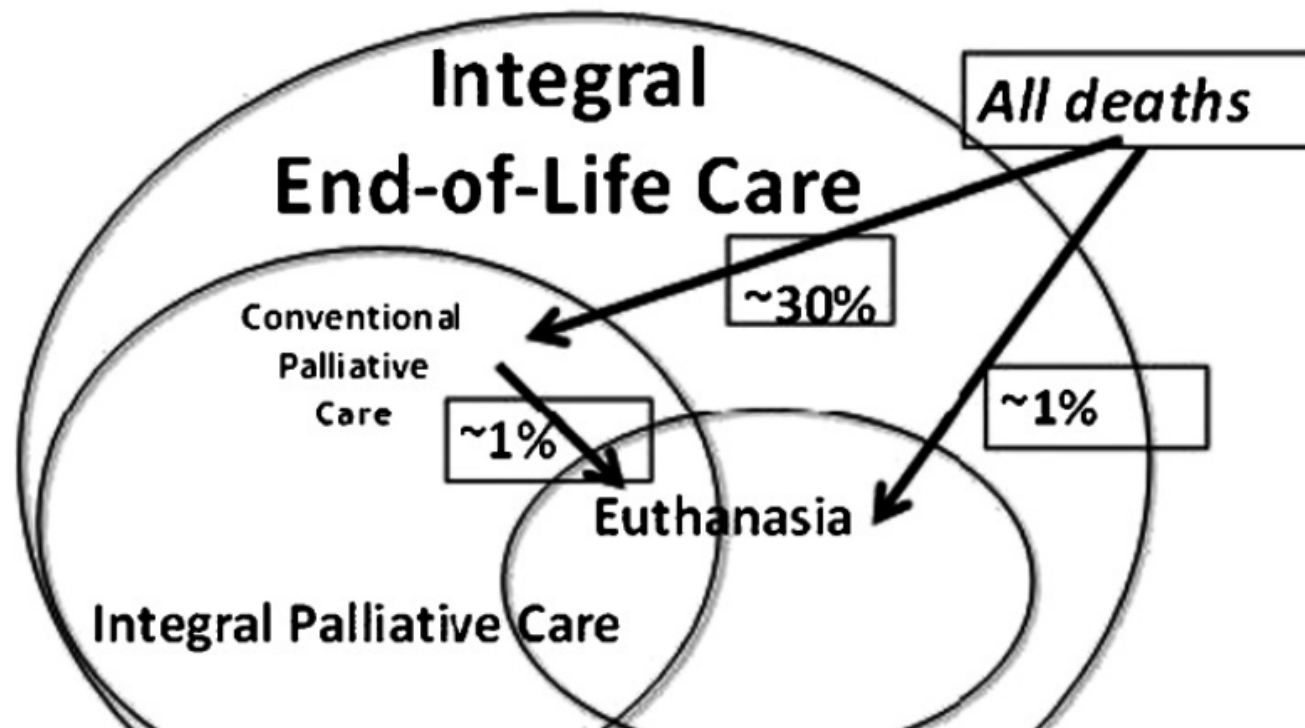
- 1998: First PPC team in Belgium
- 2002: Law on patient's right, on palliative care, on euthanasia (for adults)
- 2010: Royal Decree financing 5 PPC teams
- 2014: Law on euthanasia extended to minors
- 2016: Extended palliative care definition

[http://www.soinspalliatifs.be/images/pdf/Loi\\_2002\\_SP\\_-\\_MOD\\_2016\\_07\\_21.pdf](http://www.soinspalliatifs.be/images/pdf/Loi_2002_SP_-_MOD_2016_07_21.pdf)

# Conditions to request euthanasia

- Accidental or terminal disease with death expected within a short period of time (*art 2*)
- Constant, unbearable, refractory physical pain (unique psychological pain is excluded) (*art 2c*)
- Child must be conscious and make a written request (*art 2f*)
- Written consent of each parent must be obtained (*art 2f*)
- Capacity of discernment must be assessed by a pedopsychiatrist or a psychologist (*art 2d*)
- Information about possibility of psychological support must be given to family (*art 2g*)
  
- As for adults: a second physician must be consulted ; physician have a conscience clause ; the act of euthanasia is a medical one.

## The 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. Children's and adolescents voices

You should ask if I am happy!

Yes

Because my parents are always with me!

Are you happy?

Could you tell me what makes you happy?  
(researcher)

A 9-year old girl with a neurodegenerative condition, 4 members paralyzed

You are exaggerating. It's not possible. (...)

No, it's not true, I didn't asked that question, you did it! Don't confound my voice with yours. We don't have the same voice! I experience it twice more than you. I experience it better!

You see, she is living it her way,  
and I my own way,  
differently. (mother)

Yes, I'm in a good mood. I want to go out and see the dead. I won't be sad. I promise you. Please. At least, I would have seen once a dead person. Everybody will go. Why not me? Why are you frighten?

I won't be frightened, not a lot, because I asked L. how it was.  
I know it, G. is beautiful.

But what will I do if you will be frightened?  
(mother)

We didn't know what to do anymore.

Since they (the physicians) told us that they couldn't help anymore, that there was nothing to do anymore, she had told me that she would like to request it, but she didn't have the courage to fill in the documents.

Euthanasia procedure:  
an additional burden for children?

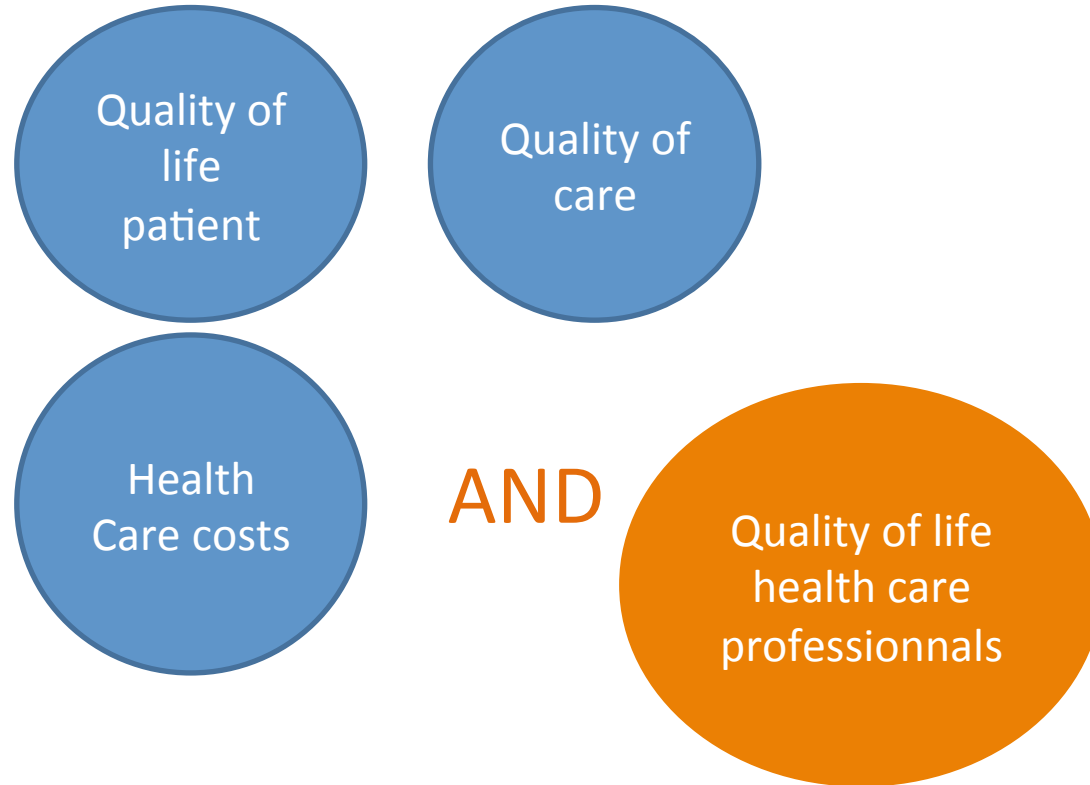
A mother talking about her 16-year old daughter who died from cancer

# 5. Discussion

- How can we provide a « holding » environment , be « a good enough » PPC team?
- How can we better listen to children's voices, knowing that they are embedded in strong relations with their parents made of loyalty, love and mutual pretense?



# Could 'Holding' also mean: providing sustainable care?



Is that the case with euthanasia?

# Take home message

- The procedure on euthanasia as formulated in the Belgian Law might not be adapted to children, regarding the concept of holding and the specific relations between children and their parents.
- Instead, honest conversations about suffering, death and wishes should be privileged to listen to children's voices.
- If needed in extreme situations of agony, the ultimate responsibility of end of life decisions should be taken by the physician himself.

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