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 Winnicott 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 intimate 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?

Legal and organizational Context
Team
School, friends
Parents, siblings
Child
Paediatric Liaison Care Model:

is ensuring continuity of care a type of holding?

- Temporal link
  - From curative to palliative stage, from life to death, from death to families’ grief

- Geographical link
  - Between hospital, home, respite house, school

- Relational link
  - Between family members, between team members and between child, family and team

Friedel et al. Soins Pediatr Puer 2014, Friedel et al. BMC Palliat Care 2018
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

Ministry of Justice, Belgian Law on euthanasia 28 mai 2002
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

Conditions to request euthanasia

- Accidental or terminal disease with death expected within a short period of time \((\text{art 2})\)
- Constant, unbearable, refractory physical pain (unique psychological pain is excluded) \((\text{art 2c})\)
- Child must be conscious and make a written request \((\text{art 2f})\)
- Written consent of each parent must be obtained \((\text{art 2f})\)
- Capacity of discernment must be assessed by a pedopsychiatrist or a psychologist \((\text{art 2d})\)
- Information about possibility of psychological support must be given to family \((\text{art 2g})\)

- As for adults: a second physician must be consulted; physician have a conscience clause; the act of euthanasia is a medical one.

4. Children’s and adolescents voices

You should ask if I am happy!

Are you happy?

Yes

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

Because my parents are always with me!

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)

A 18-year old girl with advanced cancer and her 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)

18-year old boy, with progressive neurological conditions and his mother
We didn’t knew 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 had 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?

Quality of life patient
Quality of care
Health Care costs

AND

Quality of life health care professionnals

Is that the case with euthanasia?

Quadruple aim suggested by Bodenheimer, 2014
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 responsability of end of life decisions should be taken by the physician himself.
6. References

- Le Goff A. Care et démocratie radicale. PUF, 2013. 68 p.