4TH GLOBAL GATHERING
MARUZZA CONGRESS
ON PAEDIATRIC PALLIATIVE CARE
ROME 24TH-27TH OCTOBER 2018

Non-religious arguments to discuss pediatric euthanasia:

why should pediatric palliative care use them

Joana Mendes, RN, MSc, PhD Ethics

Neonatal Intensive Care Unit, Hospital S.F.Xavier, Portugal
Taskforce of Continued and Palliative Care, Portuguese Society of Pediatrics
Ethics Taskforce, , Portuguese Association of Palliative Care
Pediatric Taskforce, Portuguese Association of Palliative Care

Marie Friedel RN, PNP, MSc, Dipl Paed Pall Care, PhD cand.

Haute Ecole Vinci, Institut Parnasse-ISEI, Université catholique de Louvain-Institut de recherché Santé et Société, Belgium.

Context

Pro-euthanasia voices are increasingly heard globally.

The debate is **sensitive** and raises **complex ethical concerns**

Netherlands

April 2001 (2002)

Euthanasia/ Assisted Suicide (>12 y)

Netherlands

September 2014

Groningen Protocol (< 1 y)

Dutch paediatricians: give terminally ill children under 12 the right to die

June 2015

Dutch Paediatric Association says country should follow Belgium in changing law on euthanasia and scrapping age limit for children in unbearable suffering

The Guardian

International edition

https://www.theguardian.com/society/2015/jun/19/terminally-ill-children-right-to-die-euthanasia-netherlands

Belgium

Euthanasia – no limit of age (Feb 2014)

3 minors were granted euthanasia [2016-2017] (9,11, 17 y)

News

Belgium authorised euthanasia of a terminally ill nine and 11-year-old in youngest cases worldwide

share

Save

The Telegraph

https://www.telegraph.co.uk/news/2018/08/07/belgium-authorised-euthanasia-terminally-nine-11-year-old-youngest/

Holding Hands or Turning's one back?

There is a growing tendency for those who support euthanasia to represent opposition to it as the result of **religious faith**, and to suggest that religious faith is at odds with clear reasoning.

Reasoning

Science
Evidence based
Autonomy
Laic society

Faith

Spirituality/Religion
Transcendency
Sanctity of life
Uncertainty- ods

Fact or a myth?

How can this interfere in the quality of the debate in a laic society?

The starting point

Debate surrounding euthanasia is often embed with unclear **definitions and messages-** sanctity of life, euthanasia, obstinacy and palliative care

Palliative Care and **Ethics** are historically linked with religion.

Spirituality is an important part of PPC, specially in end of life (broader than religiosity)

In a **laic society**, overlapping arguments with religious convictions can underestimate the quality of the debate and the accuracy of the arguments

Arguments are multidimensional: ethical, psychological considerations, state of the art or cultural and legal framework

The doctrine of double effect

Permissibility of an action that causes a serious harm

sometimes it is permissible to cause a harm as a side effect

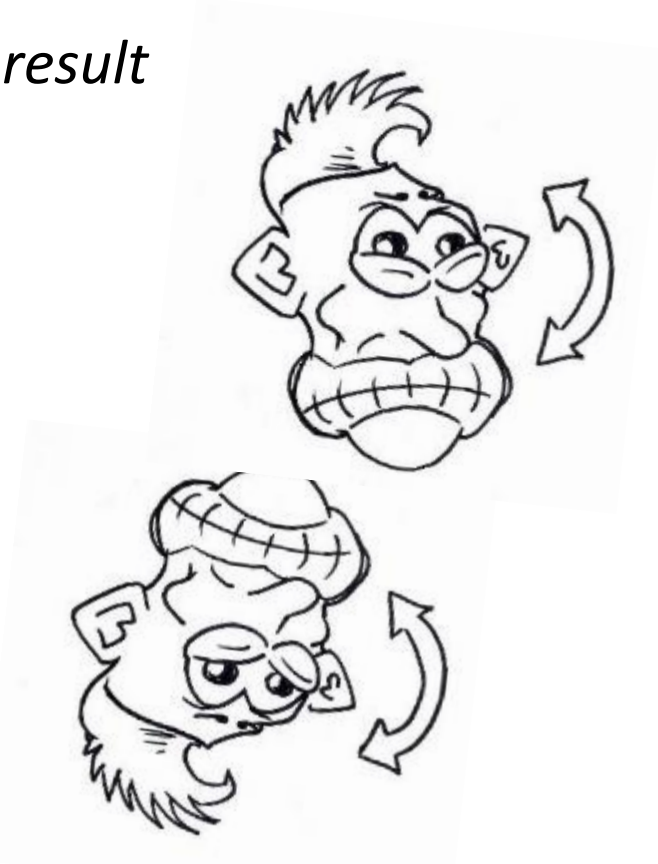
(or "double effect") of bringing about a good result

1.1. Act morally good or at least indifferent

2. Good effect and not the evil effect be intended

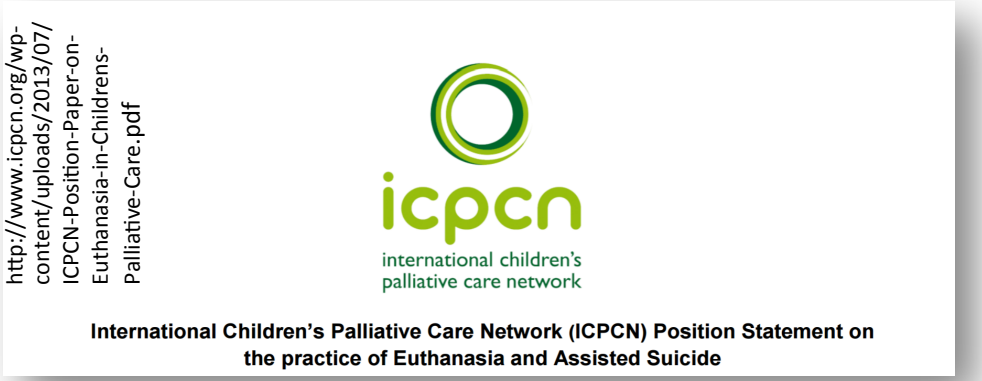
3. Good effect be not produced by means of the evil effect

4.Proportionately gave reason for permitting the evil effect



https://plato.stanford.edu/entries/double-effect/

Pediatric Palliative Care



Many requests for euthanasia or assisted suicide are made in order to draw attention to specific causes of ***emotional distress and despair****. Those can often be reversed with appropriate support*

None of the following should be seen as euthanasia:

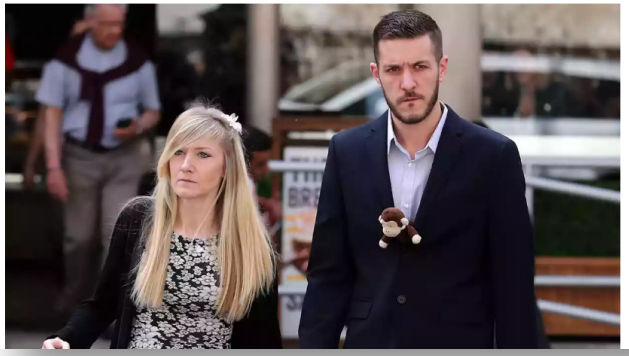
- ***Withholding treatment*** *that will do more harm than good*
- ***Withdrawing treatment*** *that will do more harm than good*
- ***Sedation*** *that is necessary for relief of distress caused by refractory symptoms*

Media *bias*?

July 2017

Charlie Gard: Pope shows solidarity with parents of critically ill 10-month-old

Pontiff asks that they be allowed to do everything possible to treat their critically ill 10-month-old son



The Guardian International edition

April 2018

Alfie Evans's father begs Pope Francis to 'save our son'

Father of seriously ill British toddler flies to Vatican to urge pontiff to intervene in legal fight

▲ James Evans, the father of Alfie Evans, kisses the pope's hand in the Vatican. Photograph: Alfies Army/Facebook

In a statement on Friday, Archbishop Vincenzo Paglia of the Pontifical Academy of Life, said: "We should never act with the deliberate intention to end a human life, including the removal of nutrition and hydration.

"We do, sometimes, however, have to recognise the limitations of what can be done, while always acting humanely in the service of the sick person until the time of natural death occurs."

https://www.theguardian.com/world/2017/jul/02/pope-shows-solidarity-with-charlie-gards-parents

How can this interfere on the quality of the debate?

Religious convictions and palliative care on **the same track**?

If I am Catholic what option should I defend?

Is **withdrawal of medical interventions** ethically permissive?

What is the **value** of sanctity of life, quality of life and dignity?

How to go defend child's best interest?

…

New ethical challenge?

Bambino Gesù
OSPEDALE PEDIATRICO

Charter of Rights
OF THE INCURABLE CHILD

BioEdge bioethics news from around the world

Friday, October 26, 2018 in depth | pointed remarks | abou

Vatican-backed hospital proposes charter of rights for incurable children

by Michael Cook | 2 Jun 2018 | 1 comment

https://www.bioedge.org/bioethics/vatican-backed-hospital-proposes-charter-of-rights-for-incurable-children/12716

The child has right to have access to the best available **experimental treatment**

The child has the right to be **respected as a person** even in the end-of-life phase, refraining from therapeutic obstinacy

The child has right to continue care and **palliative care**

The child has right to **transboundary healthcare**

Conclusions

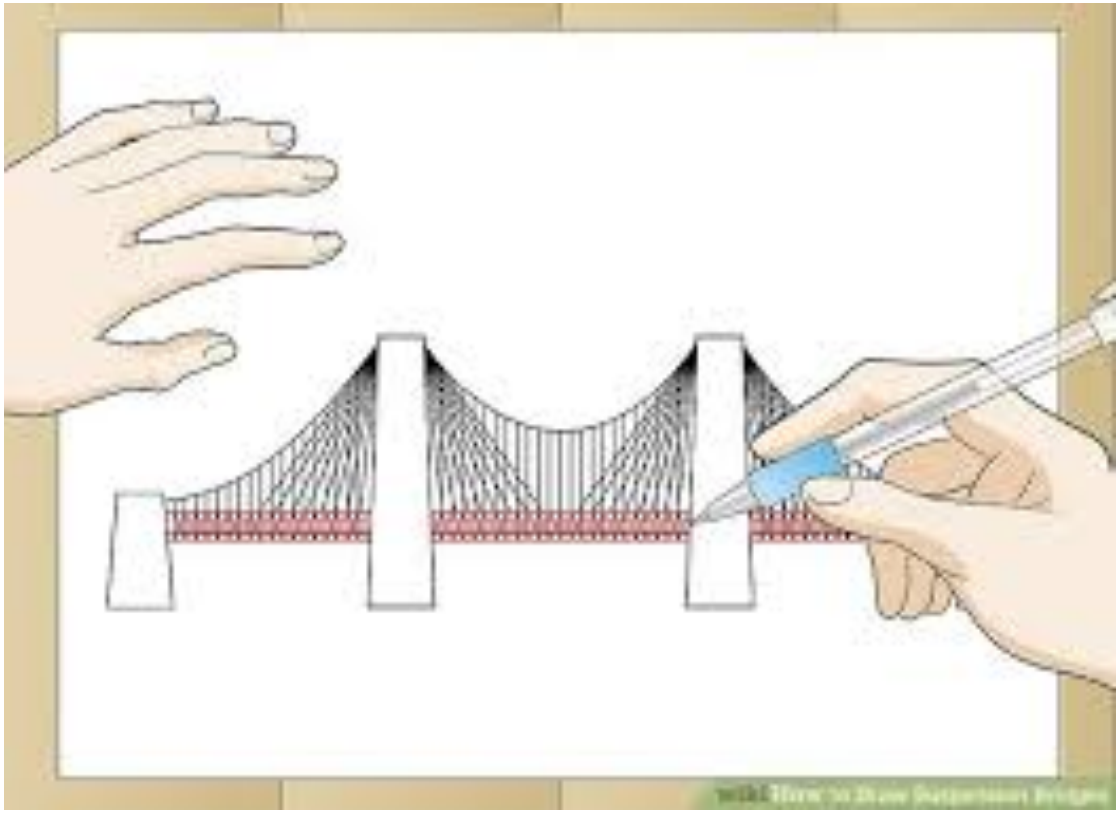
Debate surrounding pediatric euthanasia is **inescapable**, **challenging** and **emerging worldwide**.

Reducing the debate to religious arguments alone *[amplified by the bias of media coverage]* **impoverishes the debate and perpetuates misunderstandings.**

The misperception that opposition to euthanasia is the result of religious conviction undermines the debate, and so **threatens the possibility of improving the care of children at the end of life**.

Conclusions

Defenders of PPC against euthanasia must set out **convincing, well-reasoned arguments** and avoid reinforcing the illusion that opposition to euthanasia is driven by religious conviction alone.



joanaccmendes@hotmail.com