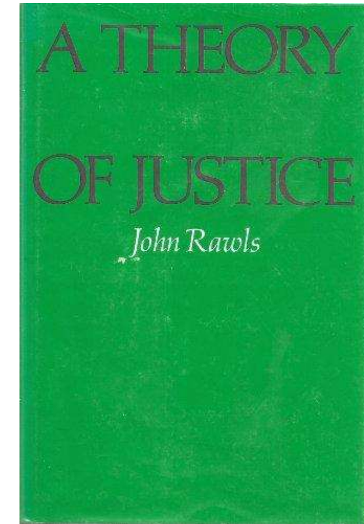
Working with Respect for the *Best Interest* of the Infant

Oswald Hasselmann
St.Gallen

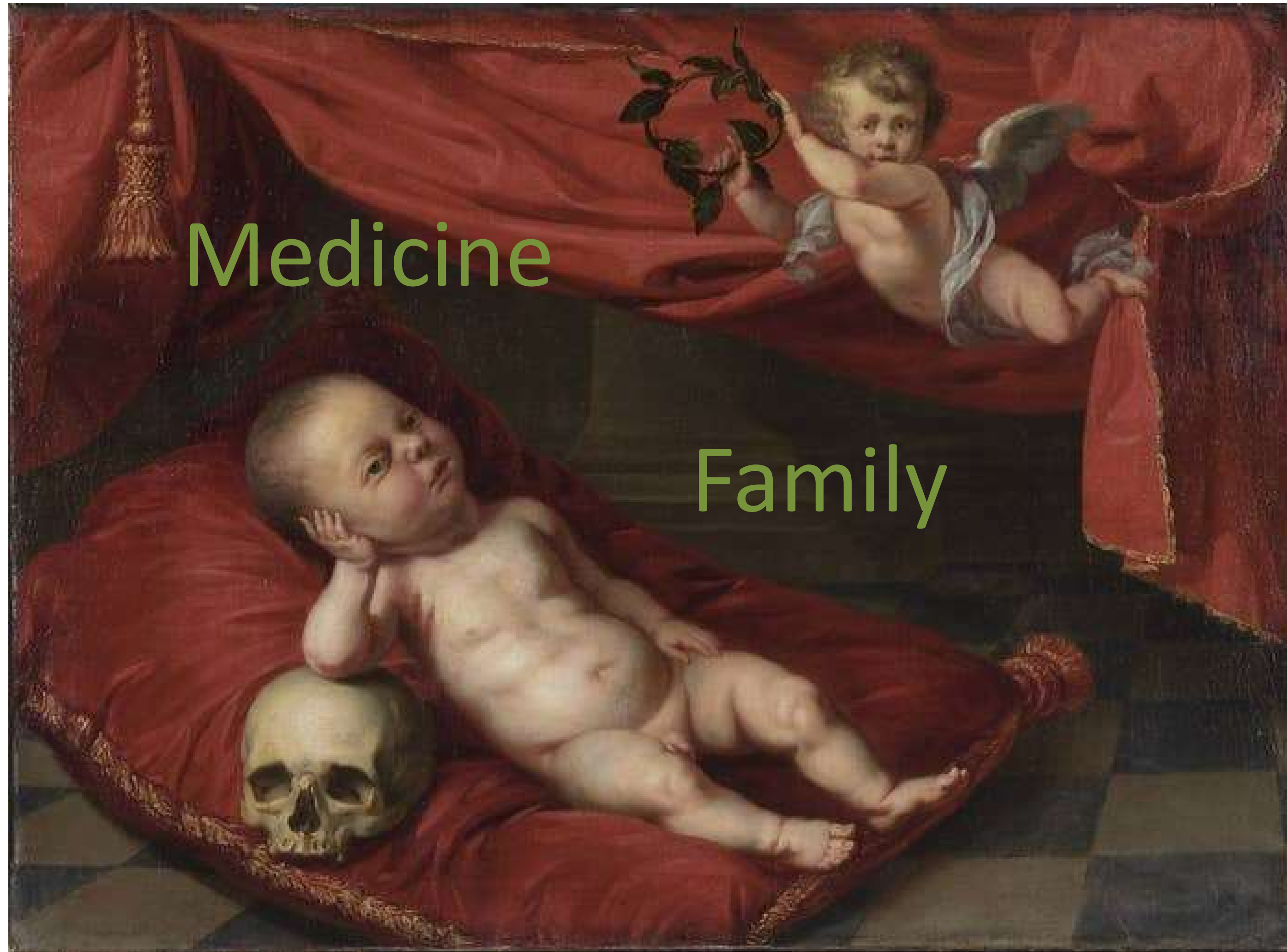
Aim: Good clinical Practice

- Conceptual challenges
- Implementational challenges



Make the worst outcome as least bad as possible

The Person concerned



Focus: Ethical Challenges in the Care of very sick Infants

Introduction

- PGD – Abortion, the Iranien Perspective
- Home birth for Neonates with life limiting diseases
- Communication with families of Neonates
- Data on Mortality – Geneva
- Termination of late Pregnancy

Appreciation

Reuptake tomorrow:

- Shared Optimum Approach

Procreative Beneficence: Obstetrician

PGD: Substituted Judgement

An epistemic Problem

- Facing hardship: Is his/her Life worth living?
- Burden of treatment and Burden of life
- Enjoyment of deep personal Relationship
- Where are the Tresholds?
- *As Death is inevitable, should the*

whole book be left out, if it is a bad one? *Savulescu*

This article was published in the *Cambridge Quarterly of Healthcare Ethics* in 1997.

Do Physicians' Own Preferences for Life-Sustaining Treatment Influence Their Perceptions of Patients' Preferences? A Second Look

LAWRENCE J. SCHNEIDERMAN, ROBERT M. KAPLAN, ESTHER ROSENBERG, and HOLLY TEETZEL

Informed Consent

- → obligation to identify the **values of patients** before making any recommendation?
- **Shoulder dystocia - cerebral palsy**: *UKSC 11 2015*
- *Would a reasonable person in the patient's position or the particular patient would be likely to attach significance to the three exceptions:*
- 1. Patient prefers not to know,
- 2. Disclosure of risks is detrimental,
- 3. Patient is not able to give the consent

Beneficient Care

- **Life-limiting fetal conditions**
- Old school: Termination of pregnancy **vs.** postnatal resuscitation and life-prolonging treatment
- New: Ameliorate suffering, honore parents values
- Avoid ambiguous, value-loaded Terminology such as: *incompatible with life*, *futile* …
- Respecting needs of fetus **and** parents: diagnosis -> birth -> possible death -> bereavement period
- Secure safe place for Parenting

Neonatologist

Life-sustaining treatment?

- Cave: Opinion disguised as data

- No agreement on *lethal* condition -> *futility*
- *Label* can take away decision-making from parents: wether: Fetal monitoring, Cesarean section, CPR
- No Data: How Parents' long-term well-being is dependent on ante- and postnatal decisions?
- Aim: Enable time with the child, while still alive!

Ensuring Capabilities and Rights

- To do, to be what they have reason to value
- Agency, not solely relying on utility
- Bodily integrity, senses, imagination, affiliation …

- **Childrens right** (1918)
- … to fail
- … to die prematurely
- … to live in the present
- … to be himself or herself
- … to be appreciated for what (s)he is

J. Korczak 1990 Andrzej Wajda

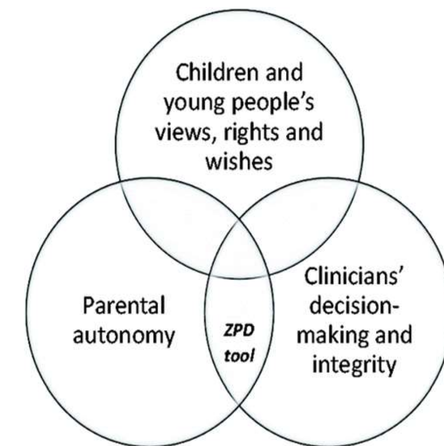
Amartya Sen Commodities and capabilities (1985)

Zone of Parental Discretion

Parents and Charlie Gard

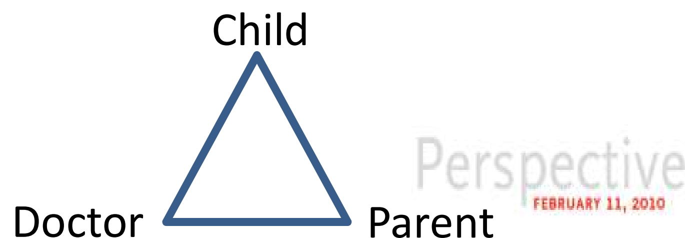
- Embedded interests with the duty/right to care
- Guilt, overburdened, perceive reduced Q.o.L.

- "If they lost their current abilities, would they want a continuation of treatment?"



McDougall, R, Gillam, L, Gold, H. The zone of parental discretion. In: McDougall, R, Delany, C, Gillam, L (eds)
When Doctors and Parents Disagree: Ethics, Paediatrics and the Zone of Parental Discretion. Sydney: Federation Press, 2016, pp. 14–24

An Example of Shared Responsibility



Is It Always Wrong to Perform Futile CPR?

Robert D. Truog, M.D.

- Child beyond suffering
- Interests of the patient begin to wane, while those of the family intensify.
- CPR for the sake of the family who didn't accept reality as we saw it.
- *I want to thank you. I can see from this that you really tried; you didn't just give up and let him die*.

- *Caveat*: Nonbeneficial CPR should never be performed when it would cause substantial suffering or when the demands of the family are clearly at odds with the interests of the patient.

The Ethical Framework

- The parental task
  of deciding
- The focus on
  this particular child
- The medicinal task of
  accompanying
- The art of communicating
- The art to
  enable and to accept