What is Patient Centred Care? What is Family Centred Care? What is Patient and Family Centred Care?

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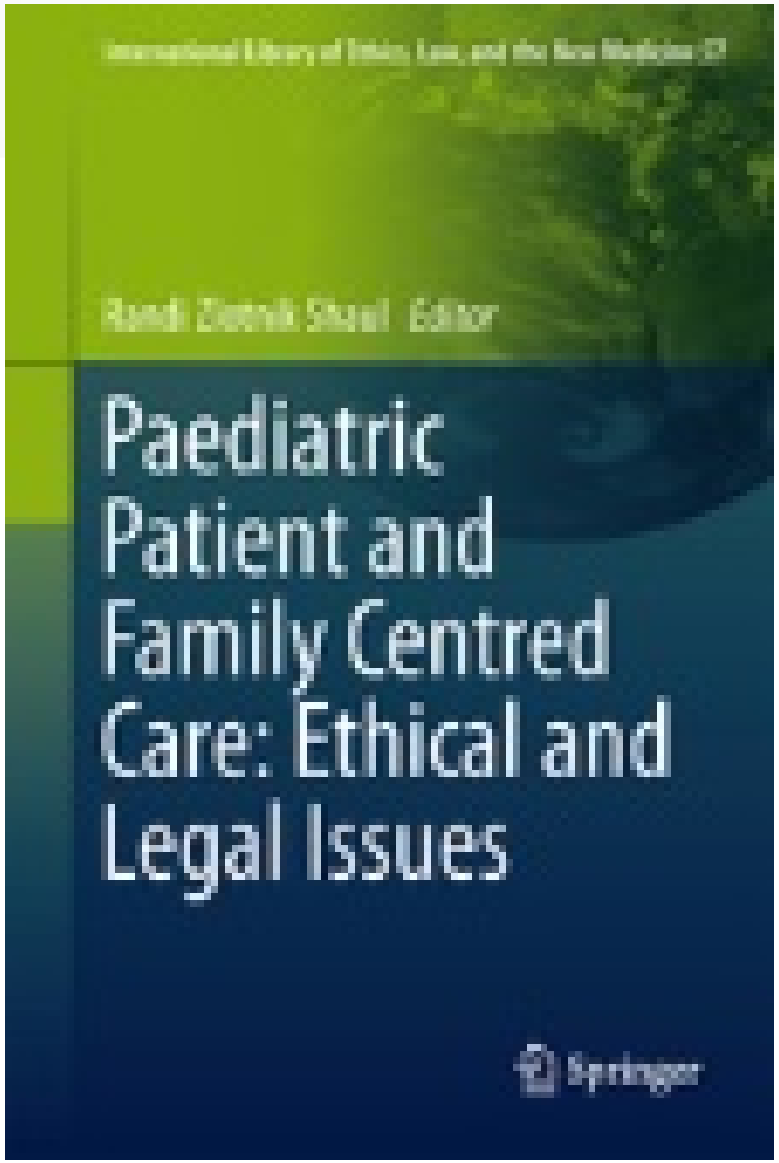
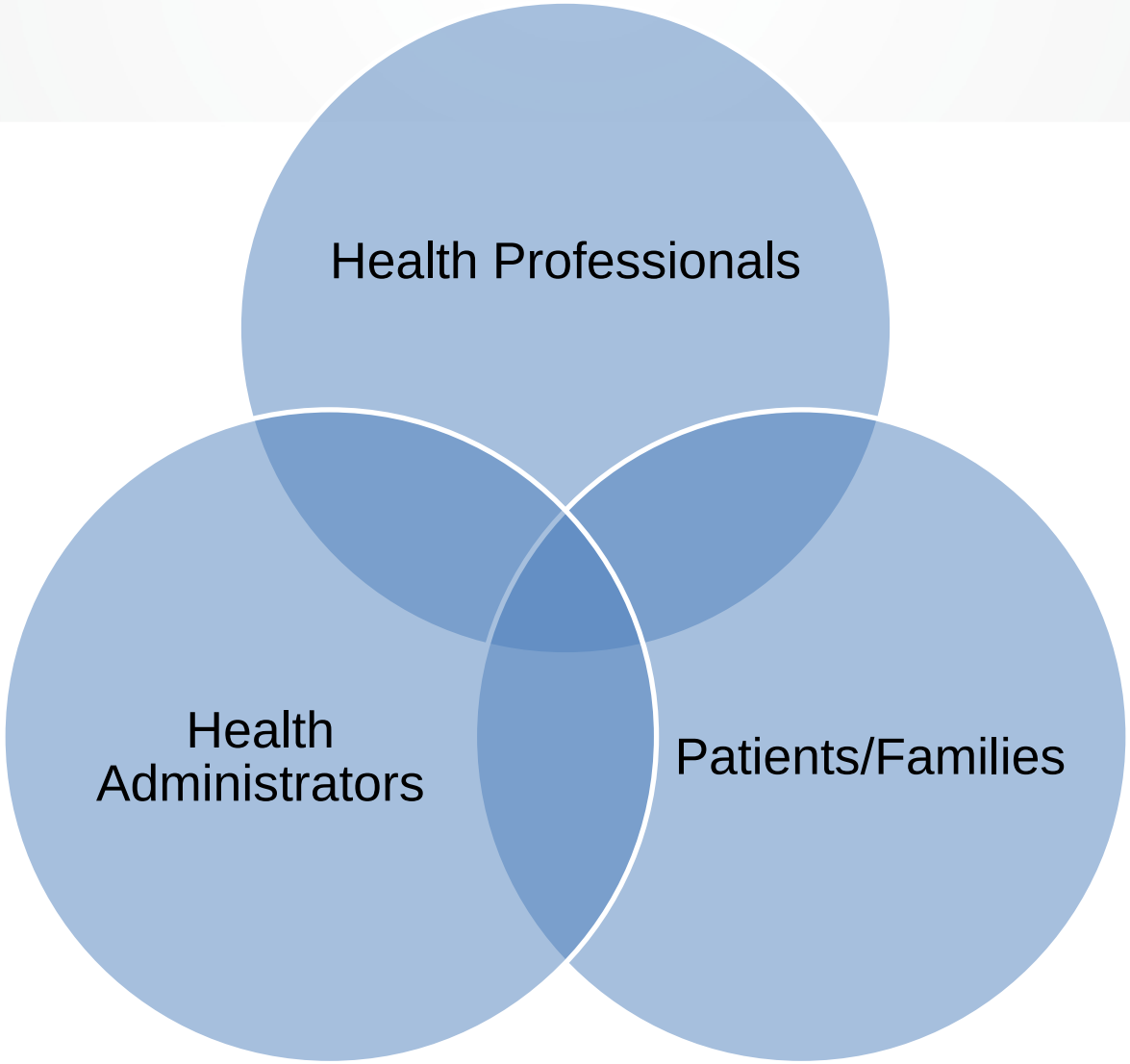

Paediatric Patient and Family Centred Care: Ethical and Legal Issues
Springer

Why this talk now?

Driven from observation of clinical situations where the values espoused by the philosophy of ‘family-centred care’ have cause conflict or confusion for professionals in their role as advocates.


Health Professionals
Health Administrators
Patients/Families

Ethics in one slide:

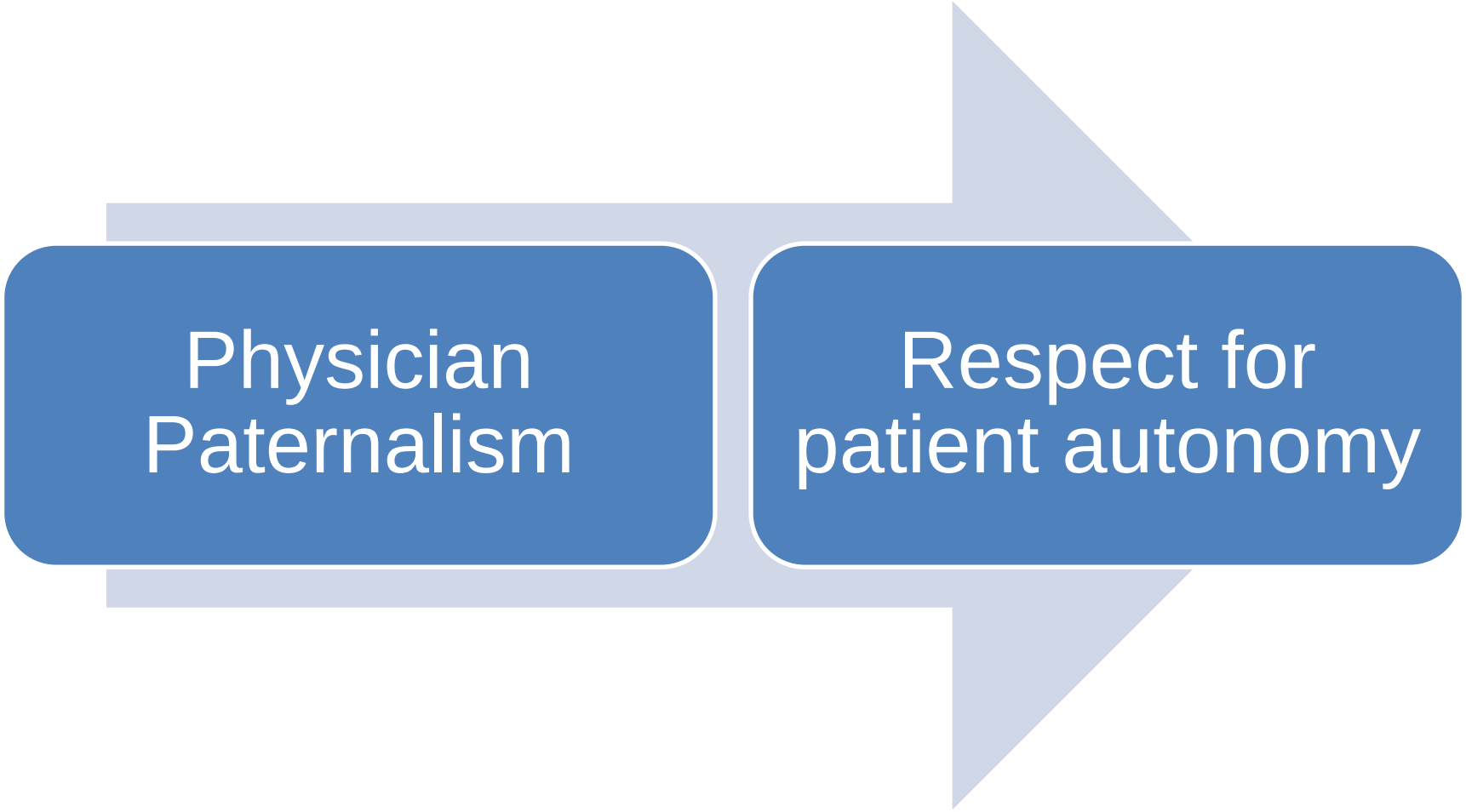
The New Question: What makes right actions right?

The Old Question: What is the good life? (Eudaemonia)

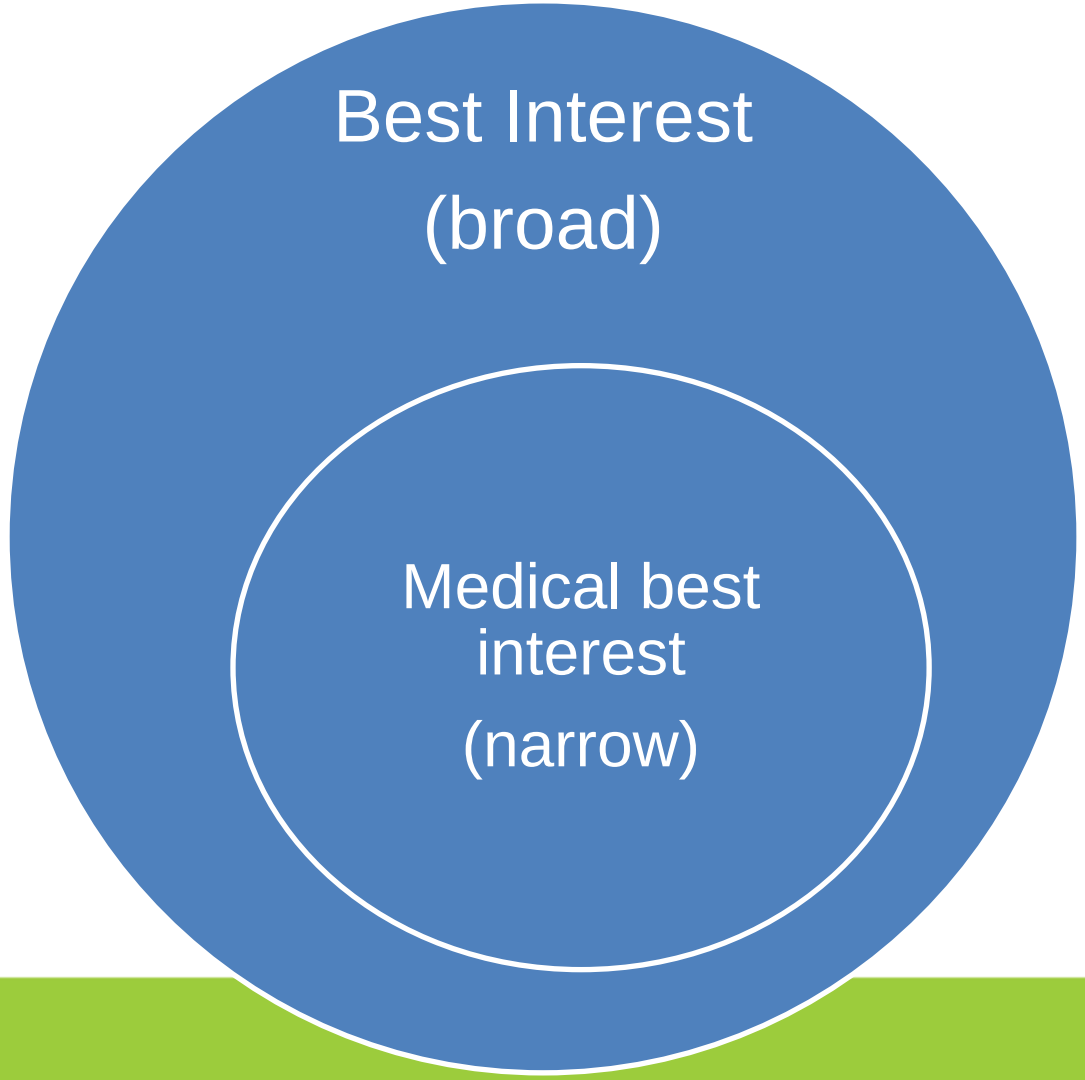
Richard Taylor, Good and Evil (1970)

Patient-Centred Ethics

The ethical paradigm shift



The ethical paradigm shift



consent

- voluntariness
- capacity
- disclosure

The psychological paradigm shift

The rational agent	Psychometric risk paradigm
• Philosophical assumption about human nature • Legal assumption guiding clinical practice via consent (the reasonable person)	• Decisions regarding risk influences but multiple factors including affect, stigma, emotion, etc. • Decisions vulnerable to ubiquitous cognitive biases

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Baruch Fischhoff: *Risk Analysis*, vol. 15(2) 1995.

- First Developmental Stage: "All We Have to Do is Get the Numbers Right“
- Second: "All We Have to Do is Tell Them the Numbers“
- Third : "All We Have to Do is Explain What We Mean by the Numbers“
- Fourth : "All We Have to Do is Show Them That They've Accepted Similar Risks in the Past"

Baruch Fischhoff: *Risk Analysis*, vol. 15(2) 1995.

- Fifth : "All We Have to Do is Show Them That It's a Good Deal for Them“
- Sixth : "All We Have to Do is Treat Them Nicely“
- Seventh : "All We Have to Do is Make Them Partners"

Professional Ethics

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- covanental relationship
- eudaemonistic
- ultimately reducible to the fiduciary relationship

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- covanental relationship
- eudaemonistic
- ultimately reducible to the fiduciary relationship
- health professionals ultimately and fundamentally are advocates for a patient's best interest. This amongst all others can be considered the ultimate value in healthcare.

Organizational Ethics

Organizational Ethics

- differing focus at different levels bedside (micro), meso, and macro.
- should support organization's mission
- cannot function without an understanding of the topography and anthropological essence of an organization.

What is patient-centred care?

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It is done well when clinicians can ethically combine both communication and advocacy.

It is done well when the process of obtaining consent is understood as communication between experts.

What is Family Centred Care?

- **Respect and dignity.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

What is Family Centred Care?

- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

What is Family Centred Care?

- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

What is Family Centred Care?

- **Collaboration.** Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Alternative Models

- Hellen Harrison's normative model

Pediatrics November 1993, VOLUME 92 / ISSUE 5

The Principles for Family-Centered Neonatal Care

Helen Harrison's Principles for Family-Centered Neonatal Care

2. *To work with professionals in making informed treatment choices, parents must have available to them the same facts and interpretation of those facts as the professionals, including medical information presented in meaning formats, information about uncertainties surrounding treatments, information from parents whose children have been in similar medical situations, and access to the chart and rounds discussions*

Helen Harrison's Principles for Family-Centered Neonatal Care

3. *In medical situations involving very high mortality and morbidity, great suffering, and/or significant medical controversy, fully informed parents should have the right to make decisions regarding aggressive treatment for their infants*.

Helen Harrison's Principles for Family-Centered Neonatal Care

4. *Expectant parents should be offered information about adverse pregnancy outcomes and be given the opportunity to state in advance their treatment preferences if their baby is born extremely prematurely and/or critically ill*.

Helen Harrison's Principles for Family-Centered Neonatal Care

9. *Parents and professionals must work together to promote meaningful long-term follow-up for all high-risk NICU survivors*.

What is Patient and Family Centred Care?

Challenges of organizational philosophy…


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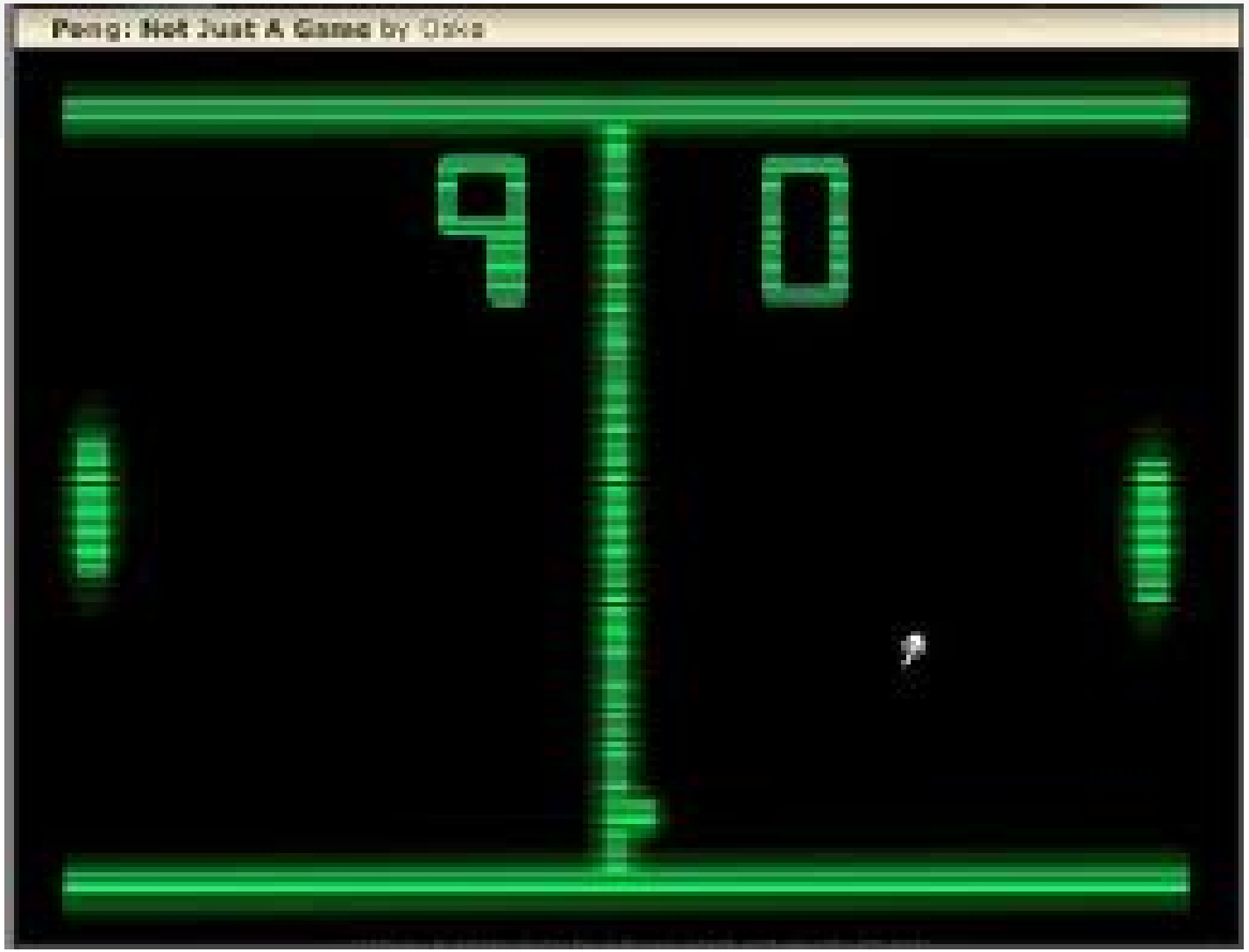
Pong: Not Just A Game by Oslo
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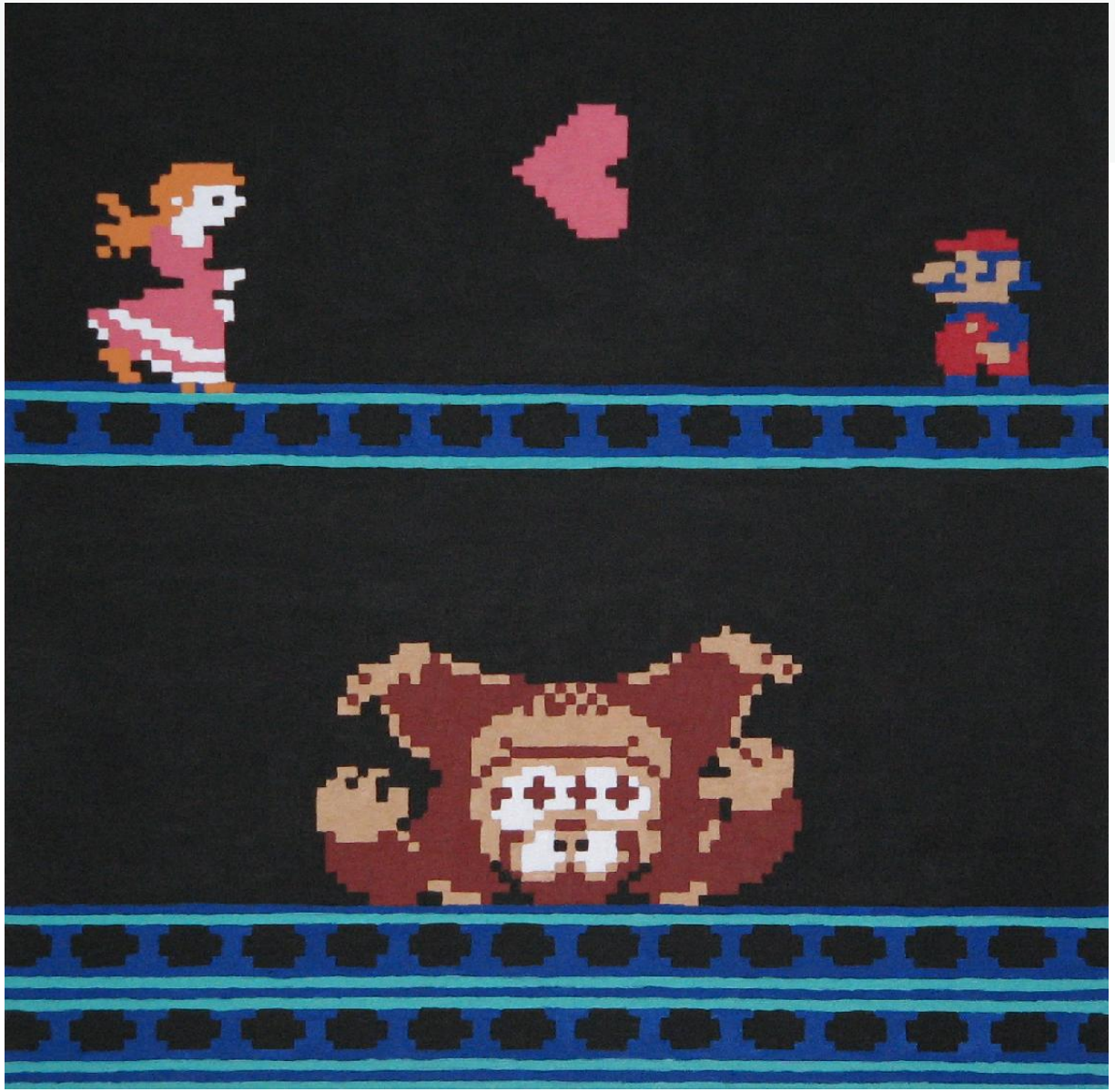

Challenges of innovating organizational philosophy…

Weak dangers: confusion of roles, misinterpretation of philosophy, ambiguity.

Challenges of innovating organizational philosophy…

Dangerous Forms:

Challenges of innovating organizational philosophy…

Dangerous Forms:

Intentionally or unintentionally shifting the balance of unresolved tensions: e.g. the problem of paediatric best interest (severely premature resuscitation, congenital heart repair of Trisomy 18 babies, transplant contrary to family wishes, etc)

Guidelines on giving intensive care to extremely premature babies

- **At 25 weeks and above**
  Intensive care should be initiated and the baby admitted to a neonatal intensive care unit, unless he or she is known to be affected by some severe abnormality incompatible with any significant period of survival.
- **Between 24 weeks, 0 days and 24 weeks, 6 days**
  Normal practice should be that a baby will be offered full invasive intensive care and support from birth and admitted to a neonatal intensive care unit, unless the parents and the clinicians are agreed that in the light of the baby's condition it is not in his or her best interests to start intensive care.
- **Between 23 weeks, 0 days and 23 weeks, 6 days**
  It is very difficult to predict the future outcome for an individual baby. Precedence should be given to the wishes of the parents. However, where the condition of the baby indicates that he or she will not survive for long, clinicians should not be obliged to proceed with treatment wholly contrary to their clinical judgement, if they judge that treatment would be futile.
- **Between 22 weeks, 0 days and 22 weeks, 6 days**
  Standard practice should be not to resuscitate the baby. Resuscitation should only be attempted and intensive care offered if parents request resuscitation, and reiterate this request, after thorough discussion with an experienced paediatrician about the risks and long-term outcomes, and if the clinicians agree that it is in the baby's best interests.
- **Before 22 weeks**
  Any intervention at this stage is experimental. Attempts to resuscitate should only take place within a clinical research study that has been assessed and approved by a research ethics committee and with informed parental consent.

CLINICAL ethics

CPSO policy statement on cpr

- :“**A decision regarding a no-CPR order cannot be made unilaterally by the physician**. Where a physician is of the opinion that CPR should not be provided for a patient & that a no-CPR order should be written in the patient’s record, the College requires physicians to discuss this with the patient and/or substitute decision-maker at the earliest and most appropriate opportunity, and to explain why CPR is not being proposed. This discussion must occur before a no-CPR order can be written.

CPSO policy statement on cpr

- If the patient or substitute decision-maker disagrees and insists that CPR be provided, physicians must engage in the conflict resolution process as outlined in Section 8 of this policy which may include an application to the Consent and Capacity Board. Physicians must allow the patient or substitute decision-maker a reasonable amount of time to disagree before a no-CPR order can be written.

CPSO policy statement on cpr

- **While the conflict resolution process is underway, if an event requiring CPR occurs, physicians must provide CPR. In so doing, physicians must act in good faith and use their professional judgment to determine how long to continue providing CPR.”**


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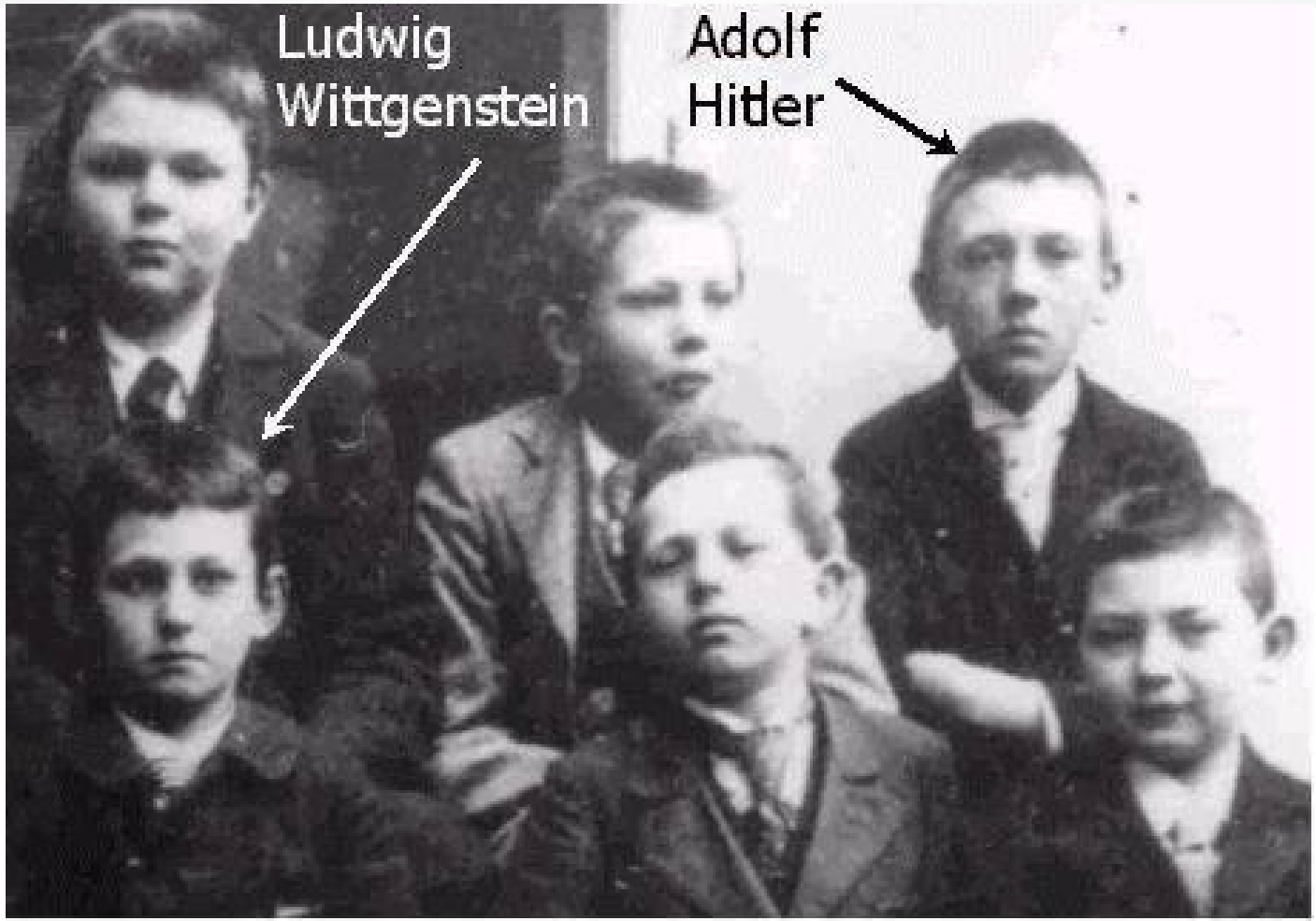
Ludwig
Wittgenstein
Adolf
Hitler