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

Brendan Leier PhD
Clinical Ethicist UAH, MAMI, and Stollery Hospitals
Assist. Clinical Professor, FOMD
Dossetor Health Ethics Centre

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.
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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 (1976)
Slide 7

The ethical paradigm shift

Physician Paternalism  
Respect for patient autonomy

Slide 8

The ethical paradigm shift

Best Interest (broad)  
Medical best interest (narrow)

Slide 9

consent

- voluntariness
- capacity
- disclosure
The psychological paradigm shift

The rational agent

- Philosophical assumption about human nature
- Legal assumption guiding clinical practice via consent (the reasonable person)

Psychometric risk paradigm

- Decisions regarding risk influences but multiple factors including affect, stigma, emotion, etc.
- Decisions vulnerable to ubiquitous cognitive biases

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"

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Professional Ethics

- covenental relationship
- eudaemonistic
- ultimately reducible to the fiduciary relationship
Professional Ethics

- covenantal 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

- 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?

Patient-centred care is the concerted effort by teams of health-providers to facilitate decision-making under uncertainty. It is done well when clinicians can ethically combine both communication and advocacy.
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What is patient-centred care?

Patient-centred care is the concerted effort by teams of health-providers to facilitate decision-making under uncertainty. 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.

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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.

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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
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 meaningful 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.

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.

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…
Challenges of innovating organizational philosophy…

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

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).

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.

Those who stir the shit pot should have to lick the spoon