We Can But Should We? The Ethics of Pediatric Kidney Transplantation

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What’s in a talk

- In the spirit of social work week (our lens)
- “Catalyst for discomfort” (Dr. David Sylvester)
- Interdisciplinary process
- Ethics and the law perspective
- No Answers only Questions !!!
“Learning is not a spectator sport…”
Quick tutorial on Chronic kidney disease

- 59 children on renal replacement in Canada (CORR, 2013)
- Transplant “standard of care” in pediatric CKD (5yr - 97%)
- Transplant / dialysis as treatments not cures. No treatment = death
- One year survival rate for children requiring dialysis in first year of life 84% - 71% year three (CORR, 2013)
- Dialysis therapy associated with an appreciably higher risk of death (4 times) when compared to transplant. Longer period on dialysis associated with poorer outcomes for children (NAPRTCS)
- Regional issues (Four centres) – London patients transplanted at HSC (Toronto)
What is the impact of Pediatric CKD?

**For Children:**
- Delayed development of social capabilities; prolonged parental dependence; higher rates of unemployment as adults and lower levels of educational attainment (Cransberg et al, 2006)
- Delayed psychosexual development, decreased autonomy and increased emotional difficulty as adults (Aldridge, 2008)

**For Parents:**
- Lack of control over the lives of their children (Tong et al, 2008)
- Depression and psychosomatic complaints (Sallfors & Hallberg, 2003)
- Burden of care and chronic uncertainty (Tong, 2010)
- Emotional and physical exhaustion (Sherrie-Coffey, 2006)
So how do we begin...
The Case of M

• 28 week pregnant Mennonite couple presented to Children’s because of abnormal prenatal ultrasound

• Old Order Mennonite, No OHIP, community minded, rural existence.

• Parents informed that kidney anomalies (bilateral renal cystic dysplasia) carried poor prognosis at birth and renal replacement therapy explained to them and potential complications

• Parents voiced they did not want dialysis/transplantation. Born (2004) not requiring dialysis, spent 22 days in hospital. (intubated)

• During hospitalization parents voiced again not wishing dialysis/transplantation and were supported by ‘team’ with their decision. M was discharged home to the care of parents.
• Conservative management until 2006 when her growth and development became an ‘issue’ for discussion. Did not require dialysis and team entered into written document outlining conservative management. Parents voiced not wanting dialysis/transplantation.

The Case of M

- Late 2008/2009 discussions regarding ‘quality of life’, “standards of care for children with ESRD” began to surface...general uncomfortableness “to let things’ go” based on her age. Parents open to education and continue to bring her to clinic however voiced no desire for dialysis and transplantation

- Feb 2009. Parents approached regarding team concerns 1) Neurodevelopment 2) Mortality and Morbidity rates 3) success rates of dialysis / transplantation 4) what is in her ‘best interests’
Parents/Family:
• Quality of Life of M
• Best Interests of M
• Faith/Spirituality
• Financial costs (community)

Team:
• Quality of life/ death
• Best Interests
• Medical/ Legal
• Standard of Care
Why is Interdisciplinary Common Ground So Difficult?

- Individual/family self determination?
- Societal views on the death of children
- Medical/Legal issues i.e., Child & Family Services Act
- Scientific knowledge vs. ‘lay’ knowledge
- Competing discourses i.e., ‘best interest’; ‘quality of life’; ‘best outcomes’.
- Power of professionals
How to move forward?
Ethical and Legal Considerations
Obligations

Legal
Absolute
No exceptions

Ethical
Can Conflict
Requires Prioritization
What are our obligations re: M?

- Ensure options, risks, benefits are understood
- Protect interests of incapable patient
- (Respect cultural differences)
- ...
- ...
- ...
Ethical Relativism

• *What do we mean by “respecting cultural differences”?*

• Principles of Biomedical Ethics – What do you think No. 1 is?
  1. 
  2. 
  3. 
  4. 
Devil in the Details

• **Child and Family Services Act [1990]**
  • Sec 72(1) Duty to Report
  • There is a risk that the child is likely to suffer physical harm inflicted by the person having charge of the child or caused by or resulting from that person’s failure to adequately care for, provide for, supervise or protect the child.

• **Health Care Consent Act [1996]**
  • Sec 21 Principles for Giving or Refusing Consent
  • A person who gives or refuses consent to a treatment on an incapable person’s behalf shall do so in accordance with ... the incapable person’s best interests.
Q. Is there a reporting obligation for M?

• “There is a risk that the child is likely to suffer physical harm inflicted by the person having charge of the child or caused by or resulting from that person’s failure to adequately care for, provide for, supervise or protect the child.”
Healthcare Workers Fear of CAS

• Justified?

With no real alternative judge divides a sick boy between family, caregivers

CHRISTIE BLATCHFORD
HAMILTON, ONT. — From Wednesday’s Globe and Mail
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The Other Side of the Coin

Clinical Assessment
- diagnosis, prognosis, consultations

Values Assessment
- patient's goals of care, personal values, wishes, beliefs

Treatment Options
- determine which treatment(s) are compatible with standard of care (indication)

Treatment Selection
- patient/SDM (and physician) eliminate options that are not compatible with patient values/goals

Consent / No Consent
- patient decision OR SDM decision in compliance with Sec.21 HCCA


Available on ChELO Website http://www.williamoslerhc.on.ca/body.cfm?id=82
Principles of SDM’ing

There are two rules for success:
1. Never tell everything you know.

Roger H. Lincoln
Best Interests (HCCA)

(2) In deciding what the incapable person’s best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

(a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;
(b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and
(c) the following factors:

1. Whether the treatment is likely to,
   i. improve the incapable person’s condition or well-being,
   ii. prevent the incapable person’s condition or well-being from deteriorating, or
   iii. reduce the extent to which, or the rate at which, the incapable person’s condition or well-being is likely to deteriorate.

2. Whether the incapable person’s condition or well-being is likely to improve, remain the same or deteriorate without the treatment.

3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.

4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed. 1996, c. 2, Sched. A, s. 21 (2).
The Consent & Capacity Board

- Lesser known obligations outlined in HCCA
- Form A
- Form C
- Form G
- www.consentqi.ca
What does Best Interests mean in end of life scenarios?

SDM

- Relevance of God or religion
- Emphasis on own values
- Patient values suffering*

Clinician

- Focus on clinical evidence
- Inability to benefit
- Likelihood to harm
- Alternative treatment (palliative) available

Board

- Distinction between wishes and values
- “condition” more than life itself
- Religious values can be considered only if demonstrated to be held by patient
- SDM focused too stringently on patient values
History of CCB Involvement in End of Life Decisions

- Only 4 of 29 cases involve children
- 2 of the 4 these were physicians arguing for life saving intervention

End of Life Cases Heard by CCB

- Unreported
- Form D
- Form C
- Form G

Re: (HJ), Scardoni v. Hawryluck
Best Interests (HCCA) in Paediatrics?

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Thought Experiment – The “24 weeker”

- 50% survival
- Neurological problems include apnea of prematurity, hypoxic-ischemic encephalopathy (HIE), retinopathy of prematurity (ROP), developmental disability, cerebral palsy and intraventricular hemorrhage, the latter affecting 25 percent of babies born preterm, usually before 32 weeks of pregnancy. Mild brain bleeds usually leave no or few lasting complications, but severe bleeds often result in brain damage or even death. Neurodevelopmental problems have been linked to lack of maternal thyroid hormones, at a time when their own thyroid is unable to meet postnatal needs.
- Children born preterm are more likely to have white matter brain abnormalities early on causing higher risks of cognitive dysfunction. White matter connectivity between the frontal and posterior brain regions are critical in learning to identify patterns in language.[10] Preterm children are at a greater risk for having poor connectivity between these areas leading to learning disabilities.
- Cardiovascular complications may arise from the failure of the ductus arteriosus to close after birth: patent ductus arteriosus (PDA).
- Respiratory problems are common, specifically the respiratory distress syndrome (RDS or IRDS) (previously called hyaline membrane disease). Another problem can be chronic lung disease (previously called bronchopulmonary dysplasia or BPD).
- Gastrointestinal and metabolic issues can arise from hypoglycemia, feeding difficulties, rickets of prematurity, hypocalcemia, inguinal hernia, and necrotizing enterocolitis (NEC).
- Hematologic complications include anemia of prematurity, thrombocytopenia, and hyperbilirubinemia (jaundice) that can lead to kernicterus.
- Infection, including sepsis, pneumonia, and urinary tract infection
- A large study on children born between 22 and 25 weeks who were currently at school age found that 46 percent had severe or moderate disabilities such as cerebral palsy, vision or hearing loss and learning problems. 34 percent were mildly disabled and 20 percent had no disabilities, while 12 percent had disabling cerebral palsy.
Thought Experiment – The “24 weeker”

- Two families, both deliver at 24 weeks – identical pregnancies
  - Family A, struggles to find value in the potentially short and challenged life – ask to palliate
  - Family B, believes that any life is worth living and ask for full life support measures.

- Q. Would we accept both requests?

- **Problem:**
  - Legally, each decision is seen as consent/refusal of consent that is being made in the ‘best interests’ of the infant.
  - But relevant components of Best Interests, don’t seem to allow for both responses to be ok
    - Because parent/family values can’t be bestowed/ascribed to children
Infinite Regress?

(c) the following factors:

1. Whether the treatment is likely to,
   i. improve the incapable person’s condition or **well-being**,
   ii. prevent the incapable person’s condition or **well-being** from deteriorating, or
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The Invisible Tension

Family Centered
So...

1. Is transplant in M’s best interests?

2. Should you make an application to the CCB?

3. Do you need to know the answer to #1. in order to answer #2.?
Case of M

• Parents refused option of dialysis and transplantation

• Case referred to the Consent/Capacity Board

• Board ruled family was not acting in her “best interest”. Family ordered to consent to move forward with therapy.

• Received LRD (Uncle) – reportedly “doing well”
What has this case taught me?

- Process, process, process
- Be aware of our power as professionals and its presence in everything we do.
- The need to be vigilant in our role as advocates for our patients and families within the system.
- Use of Self: how our values, beliefs, judgments impact our work and to be champions of a reflective approach to practice.
Is this over yet?