

“WE CAN BUT SHOULD WE?” ‘BEST INTEREST’, ETHICS, SOCIAL WORK AND PEDIATRIC KIDNEY TRANSPLANTATION

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LIKE MINDED ??







TODAYS TALK

Picture of Mennonite child ...describe how this topic became of interest to me...from a bedside to the halls of academia. Current study of research.

Also talk about why it should be of interest to social workers and social service workers..

What is 'best interest' and how do we understand this term in our work?



BEST INTEREST ?

Ask yourself:

What does 'best interest' mean to you?

How is 'best interest' used in the context of practice?

What social processes are involved in determining 'best interest' for our individuals, families and communities?

How does it overlap in our values of self determination and do no harm?

Who ultimately decides 'best interest'?

QUICK TUTORIAL ON CHRONIC KIDNEY DISEASE (CKD) IN CHILDREN ?



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

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 IMPORTANT TO KNOW ABOUT CKD

Dialysis and transplantation are treatments not cures. Not if the transplant will fail but when.

- Psychosocially intrusive for patient and family
 - Research – even when children are doing clinically well parents continue to be challenged (Creemens et al, 2004)
- Resource intensive
- The gold standard for care in pediatric end stage renal disease.
- Social discourse of transplantation i.e. gift / cure.

THE CASE OF M



28 week pregnant Mennonite couple presented to hospital because of abnormal prenatal ultrasound

Old Order Mennonite, No OHIP, community minded, rural, Anabaptist.

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/extubated)

During hospitalization parents voiced again not wishing dialysis/transplantation and were supported by 'team' with their decision felt they were acting in her 'best interest'. M was discharged home to the care of parents.

Child continued to be followed by hospital for five years.

THE CASE OF BABY M

- At age of 5 years old 'team' felt child should be listed for transplant (medical indications suggested this course of action) and dialysis if necessary. Parents refused.
- Cited "she could be cared for and kept reasonably comfortable at home until God saw fit to call her to her heavenly home"
- Children's Aid Consulted – no grounds for involvement – not a child in need of protection.
- Medical profession wanted to pursue 'standard of care' citing in her "best interest".
- Multiple meetings held of Interdisciplinary team as to how to proceed.

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).

BEST INTERESTS (HCCA) IN PAEDIATRICS?

- (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.
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 3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.
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Parents/Family:

Team:

Quality of Life of M
Best Interests of M
Faith/Spirituality
Financial costs
(community)

Quality of life/ death
Best Interests
Medical/ Legal
Standard of Care



THE INVISIBLE TENSION

Family
Centered



**FOR SOCIAL WORK AND
SOCIAL SERVICE
WORKERS**

- Self Determination?
- Advocate
- Do no harm ?
- Quality of life based on experiences of other families?
- In whose best interest?
- Professional / Personal / Legal / Ethical?
- Role as a member of the interdisciplinary team? (Context of Practice)

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

Use of Self



SO...

1. Is transplant in M's best interests?
2. Should you make an application to the Consent and Capacity Board?
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 (Transplant / dialysis)

Received Living related kidney.

WHAT HAS THIS CASE TAUGHT ME ?

- Be aware of our power and privilege 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.
- Reflect on notions of Family/Patient Centered care and ensure ideals and values of this approach do not get lost in the business of health care.

CASE UPDATE FIVE YEARS LATER

Interviewed mom, dad, paternal grandfather

M is "doing well" five years post transplant (two minor episodes of rejection effectively medically managed)

Would not do anything different – based on faith - "complete surrender to the will of God"

Aware of the 'inherent power differences among marginalized communities – power of their own community as it relates to relationship with mainstream health".

My own journey as social worker/researcher/oppressor?

**SO YOU'RE THE SOCIAL
WORKER OR SOCIAL
SERVICE WORKER?**

A Penny for your Thoughts

IS THIS OVER YET ?


