March 13, 2017

LCC Pediatric Ethics Cases (2 sessions)

Objectives of the Sessions:

1. To explore the concept of "best interests" and “surrogate decision-makers” in regards to decision-making in pediatrics.

2. To appreciate the evolving decision-making capacity of children.

3. To provide opportunity for residents to discuss challenging ethical cases

CanMeds roles: Professional, Advocate

Suggested reading: (CPS statements)

- **Treatment decisions regarding infants, children and adolescents**
- **Ethical participation of children and youth in medical education**
- **Ethical issues in health research in children**

Other supplemental material:
CPSO Dialogue Issue 3, 2015 “Duty to report”
http://www.cpso.on.ca/CPSO/media/documents/Policies/Policy-Items/Dialogue-articles/Duty-to-Report_2015Iss3.pdf

CPSO Consent to treatment Policy Statement #3-15
http://www.cpso.on.ca/CPSO/media/documents/Policies/Policy-Items/Consent-To-Treatment.pdf?ext=.pdf

FORMAT:
Session 1: Discussion of cases 1 & 2 and related ethical concepts

Session 2: Discussion of case 3 and Residents bring a challenging ethical case for discussion
**These cases can be forwarded to Dr. Williams for further discussion

Cases adapted from:
In the Case of Children. Ed. Baylis F, McBurney C. Hospital for Sick Children, 1993.

CASE 1 : Bobby and his mother in the ER

At 9 months of age, Bobby was brought to the Emergency Department with croup. During this brief assessment he was found to have failure to thrive and radiologic evidence of rickets chest Xray. It was also noted that he had not been immunized. He was discharged home to be followed up in clinic two weeks later to further investigate and manage his failure to thrive.

In the interim he has now developed gastroenteritis with diarrhea and vomiting, diminished oral intake and lethargy. He again presents in the Emergency Department with his mother. Further history reveals that he is on a restrictive diet, low in energy, protein, various vitamins, and minerals. The mother is a strict vegan who avoids fortified or enriched foods or vitamin–mineral supplementation.

On examination, Bobby's weight is less than the 3rd percentile; his height much less than the 3rd percentile, and his head circumference on the 50th percentile. He is held in his mother's arms and looks unwell, feverish, lethargic, and only minimally responsive. His skin turgor is decreased and his mucus membranes are dry. He has decreased muscle mass, pitting edema in his lower limbs and evidence of protein calorie malnutrition with acute gastroenteritis and dehydration.

The physician in the ER determines that Bobby should be admitted for rehydration and nutritional management. His mother, however, refuses to have him admitted to hospital. She does not believe that her son is acutely ill, nor did she think that his failure to thrive is a problem or related to his diet.

QUESTIONS

What should the physician do?
What is in the best interests of the child?
What is in the best interests of the family?
Who decides what is in the best interests of whom?
How does the child's severity of illness impact on decision-making?

CASE 2: Clark in the NICU

Clark was born at 23 weeks' gestational age to a 27 year old G3P2 mother. His birth-weight was 600g. His primary diagnosis was severe respiratory distress syndrome; he required high ventilator rates and pressures to maintain adequate oxygenation and ventilation. The parents were kept informed of their son's progress throughout the first week of life. They were assured that important decisions would be made only when consensus was reached between them and the health care team.

In the second week of Clark's life, his parents were told that his lung disease was very severe and that if he were to survive, he would likely require weeks of ventilator therapy and months of oxygen therapy. After further deterioration in his respiratory status, the probability that Clark's lung disease was irreversible was discussed with his parents and they were informed he would likely die. The long-term clinical outcome was predicted on the basis of the severity of the lung disease.

Both parents understood the gravity of the situation. The mother said that she could not think about her son dying. The health care team expressed some concern about their difficulty in establishing a rapport with the mother because she visited the unit only when conferences were scheduled. Physical fatigue, caretaking responsibilities for the other children at home, and long-distance travel limited her opportunities to visit regularly in the NICU.

All attempts to improve Clark's lung disease were unsuccessful. He was deteriorating clinically, with increasing respiratory support required to maintain barely adequate oxygenation. The attending neonatologist met again with the parents to formally discuss withdrawal of ventilatory assistance. The mother felt that it was inherently contrary to her beliefs to discontinue therapy. She did not articulate her reasons for her decision; she seemed to be a very private, introspective person. Clark's father indicated that he was comfortable with a decision to withdraw ventilatory support; he felt it was wrong to prolong his son's suffering. In fact, he said that he would have difficulty visiting his son if treatment was not withdrawn and he continued to suffer. Clark's mother remained adamant that life was important at all costs. She explained that this was not negotiable. She would not expand on the source or nature of these beliefs. The mother refused to continue the discussion and left the conference room.

QUESTIONS

1. What should be done immediately?
2. What is in the child's best interests?
3. Is it acceptable to proceed with the consent of one parent?
4. Are there morally defensible limits to parental decision-making?
5. How should the health care team respond to the mother's beliefs when she will not (cannot) explain these beliefs?

CASE 3: Jessica needs surgery

Jessica, 13 years of age, injured her right leg in a sports camp. For 2 days she had pain below her right knee; over the next week she had physio and whirlpool baths; finally, she went to the physician who found local tenderness and swelling. An X-ray was taken; it showed an apparent tumour in the bone below the right knee.

At hospital, Jessica was found to have a tumour in the right fibula, which was interpreted as being most likely osteosarcoma. There was no evidence of tumour involvement in the lungs or in other bones. The rest of the physical and laboratory findings supported the impression of clinically localized osteosarcoma. A recommendation of an above-the-knee amputation of the right leg was made, to be followed by a period of adjuvant chemotherapy.

Jessica asked if there were alternative methods of treatment, she told her parents she did not want to have her leg removed, and that she would refuse treatment. Her parents want him to have surgery and adjuvant therapy.

QUESTIONS

1. *What ethical aspects of consent are raised in this case?*
2. *Would your approach be different if Jessica were 8 years of age?*
3. *What would your approach be if Jessica, aged 13, were refusing surgery for the correction of a congenital abnormality of her right foot?*

If time permits could discuss:

- What if Jessica were refusing medical learners? Or to be involved in a research trial? But her parents wanted him to participate?