Neonatal Ethics Teaching Program

Problem Based Learning in Ethics (PBLE)

Critically Ill Newborn in the NICU

Trainee Guide

Author

Gregory Moore, MD, FRCPC, FAAP

Co-authors:

Emanuela Ferretti, MD, FRCPC
Thierry Daboval, MD, FRCPC, MSc(c)

Collaborators:

Paul Muirhead, LL.M, LL.B

Neonatal Ethics Teaching Program - Problem Based Learning in Ethics: Critically Ill Newborn by Moore, G., Ferretti, E. & Daboval, T. is licensed under a Creative Commons Attribution-NonCommercial-NoDerivs 3.0 Unported License.

First version: February 24th, 2010

Last Amended: March 20th, 2013

Table of Contents

Description of a PBLE

A PBLE teaches some of the competencies of the Neonatal Ethics Teaching Program that the NICU fellows are expected to acquire before completing their Neonatal-Perinatal Medicine training at the University of Ottawa. Furthermore, a PBLE provides trainees the opportunity to practice and learn how they would interact with a true patient in a given clinical scenario. This helps trainees improve their communication skills and application of ethical principles when they have to interact with parents in delicate, difficult, and ethically charged situations regarding either their unborn or born child. Trainees are encouraged to refer to a Procedural Form that outlines the steps they may follow during a one-on-one medical encounter and use the Standardized Patient (SP) as a teaching tool.

Objectives

1) To distinguish the three parent rationales behind the question: "If my baby was yours, what would you do?"
2) To explain the appropriate response to the parent questions: "Have you done everything you can for my baby?"

Required Reading

1) Kon AA. Answering the question: "Doctor, if this were your child, what would you do?" *Pediatrics* 2006; 118(1):393-397.
2) Gillis J. "We want everything done". *Arch Dis Child* 2008; 93(3):192-193.

Additional References

1) Balaban RB. A physician's guide to talking about end-of-life care. *J Gen Intern Med* 2000; 15:195-200.
2) Verhagen E, Sauer PJJ. The Groningen protocol – euthanasia in severely ill newborns. *NEJM* 2005; 352(10):959-962.
3) Committee on Fetus and Newborn. Noninitiation or withdrawal of intensive care for high-risk newborns. *Pediatrics* 2007;119:401-403.
4) Catlin A, Carter B. Creation of a neonatal end-of-life palliative care protocol. *Journal of Perinatology* 2002; 22:184-195.
5) National Association of Neonatal Nurses Position Statement. Palliative care for newborns and infants: position statement #3051. *Advances in Neonatal Care* 2010; 10(6):287-293.
6) de Wit S, Donohue PK, Shepard J, Boss RD. Mother-clinician discussions in the neonatal intensive care unit: agree to disagree? *Journal of Perinatology* 2012 August; 1-4. doi:10.1038/jp.2012.103.

How to prepare for this PBLE

1) Read the required readings.
2) Review, in detail, the case scenario with the SP (see Appendix A).
3) Review, in detail, the "Procedural Form: Key Components of a Medical Encounter" (see Appendix B).

PBLE Timeline

Introduction (15 min)

Practice with the Standardized Patient (40 min)

1) 25 min to cover the first meeting with the parent.
2) 15 min of discussion.

Practice with the Standardized Patient (40 min)

1) 30 min to cover the second meeting with the parent.
2) 10 min of discussion.

Conclusion (20 min)

Appendix A

Case Scenario with the standardized patient

You are about to meet Helen, the mother of Leona, after having reviewed the "**NICU Progress Note #1**". She has just finished her first visit to the CHEO NICU. **Your role as the senior NICU fellow** is to provide Helen with a clinical update and proceed with the initial shared decision-making process around Leona's care plan.

NICU Progress Note #1
24 hour old term baby girl under therapeutic hypothermia for severe HIE (Sarnat 3) after a complicated failed VBAC delivery. Apgars 0, 1, 1, 3, 3. Cord pH <6.8.
Birth weight 3.1 kg → current weight 3.3 kg

Issues:
1. Severe HIE – Sarnat 3 with seizures
2. Intubated and ventilated (secondary to initial apnea)
3. Right pneumothorax – resolving without chest tube
4. Lactic acidosis
5. Coagulopathy – DIC and thrombocytopenia
6. Anuria → Oliguria with hyponatremia
7. Transaminitis
8. Lower gastrointestinal bleeding
9. Rule out sepsis (including leukocytosis)

Status – by System:
- CNS: aEEG: severely discontinuous background plus brief 'flat' periods
  - aEEG showed possible seizures at ~8 hours of age → Phenobarbital load x 2
  - O/E: no spontaneous movement, no response to painful stimuli, pupils slightly unequal and very sluggish, DTRs difficult to elicit, flaccid tone, no suck/gag/Moro
- Resp: Minimal vent support – 30% FiO2; Breathing above the vent most of the time
  - Stable CO2 and slowly rising pH (now 7.28)
- CVS: UVC and UAC in good position; No inotropic support required
- GI: Bright red blood PR at 12 hrs of age → FFP given → no further episodes
  - AXR = no NEC but remains NPO; AST 1412, ALT 1385
- GU: Anuric from birth → minimal urine output starting at about 20 hours of age
  - TFI 40, D10W and labs show: Na 128, K 4.8, BUN 7, Cr 124
- ID: On Amp/Gent; WBC 34 with 32% left-shift
- Heme: Initial coagulopathy corrected with multiple plt, FFP and Cryo transf'ns
  - Currently: INR 1.7, Fibrinogen 3.2, PTT 44; Hgb 132, Plts 187
- Metabolics: Glucose 16.8 initially → 6.9; 1st Lactate (at 7 hrs of age) = 19.2 → 7.1

Impression/Plan: Severe HIE with guarded short term and long term prognosis. Continue current management and meet with parents as soon as possible to discuss current status and plans.

Appendix B
Procedural Form: Components of a Medical Encounter

*Note: this is a guideline of steps, they are not necessarily sequential. Many steps occur or re-occur throughout the whole encounter

CRITICALLY ILL NEWBORN
Preparation: 1. Identify the reason for consultation. If possible, determine the range of prognosis according to the patient's diagnosis, clinical status, investigations, and prognostic factors prior to meeting with parent(s). 2. Find a time and quiet place to meet with the parents in person. 3. Make the parent(s) comfortable and allow for questions (30-60 minutes). 4. If possible, have both parents present at the medical encounter. 5. Invite additional necessary parties (i.e. consultants, bedside RN, Social Worker, religious support, etc…).

Steps	Further Explanation
*** Welcome to parents & introduce yourself.** *** Introduce other attendees as needed.** *** Welcome to others (e.g. grandparents, etc…).**	To establish trustful relationship. To introduce your role and others' role(s).
*** Encourage unknown people to leave the room with parent(s)' permission** (i.e. acquaintances). *** Appropriately inquire about the father's/partner's.** **presence/absence** (if applicable).	To give them the opportunity to freely express their feelings. To acknowledge that the situation is very sensitive and delicate.
*** Be sure that the parents have seen their baby.**	To remove the element of the "unknown."
*** Refer to the baby with his/her name.**	To acknowledge the baby, not the "disease"
*** Be honest. Admit uncertainty when present.** *** Maintain eye contact.** *** Demonstrate compassion and empathy.** *"I'm sorry to be meeting you in this difficult circumstance; [Name] is very sick and I'll explain what that exactly means shortly. I'm here to help you understand what is going on and make decisions about [Name]'s care together. I can only imagine how difficult this is for you."*	To establish a trustful relationship. To ensure no misunderstanding. To demonstrate you care for their baby.

Steps	Further Explanation
*** Introduce the agenda for the initial meeting. Modify it based on parental needs or requests.**	To be clear while demonstrating how much you care for their baby. To recognize the stresses that the illness has imposed on the family.
*** Verify the level of understanding of the parents.** *"Can you give me your understanding of [Name]'s current situation?"*	To allow the parents to "drive" the interview so you can go at their pace and their level of understanding. To begin to ensure that the parent(s) are the appropriate surrogate decision maker(s) for the baby. To allow the parent(s) to state their current knowledge of the situation.
*** Clarify incomplete components of medical and social history.**	To determine pertinent information that may influence the decision, prognosis or care plan.
*** Share your knowledge/understanding of the current clinical situation with the parents using simple, non-medical terminology.** *"I will be providing you with a lot of information so please stop me anytime."* *"Some of this information will be difficult to hear but I want you to know that no matter how bad it may be, we will deal with it together."*	To be clear and direct and to empower the parent(s) to gain the information required for shared decision making.
*** Observe parent(s)' reactions and their response to the description provided by the medical team.**	To identify the level of comprehension and degree of denial. To enable the team to support the parents in keeping a realistic level of hope.
*** Evaluate parent(s)' understanding frequently and make readjustments as necessary. Offer time for parents to ask questions as often as possible.** *"I want to be certain that I have clearly explained [Name]'s medical situation. Can you tell me in your words what we've discussed?"* *"Is there anything else you need to know or understand better?"* *** Allow silence and time.**	To allow the parents to "drive" the interview so you can go at their pace and their level of understanding. To empower the parent(s) to gain the information required for shared decision making. To ensure parents are the appropriate surrogate decision maker for the baby.

Steps	Further Explanation
*** Transition to discussion about current care plan and then possible directions moving forward.** *"I'd like to discuss our current care plan for [Name] with you. We have cared and will continue to care for him/her at all times. We all want what is best for him/her."*	To notify the parent(s) of the new part of the encounter they will now be experiencing.
*** Introduce palliative care as an option as soon as the team is considering this as a management option.** *** Focus on how everything possible to <u>care</u> for the baby, with his/her best interests in mind, has been done to this point and will always continue to be done.**	To ensure parents do not feel abandoned. To create an atmosphere that focuses on the interests of the child. To minimize conflict.
*** Ask parent(s) for their thoughts and understanding about the current care plan and future options.** *** Acknowledge our prognostic limitations and the limits of epidemiological statistics.**	To avoid assumptions about parent(s)' opinions as we don't know what is best in their opinion. To decrease the cultural taboo of talking about death. To have a clear understanding of what the parents need and want from the physicians/medical team. To involve the parent(s) in the decision making and adjust their level of involvement as per their wishes and as appropriate. To maintain trust and acknowledge the individual.
*** Obtain clear consent for the care plan.** *** Support parent(s) decision on care plan, if appropriate.** *"I admire your brave decision. I can't even imagine how difficult this must be. We will continue to support you and give the best possible care to your baby every moment of the day."*	To ensure parent(s) feel secure and supported in their decision. To confirm their decision and ensure that they feel supported. To be able to move towards clarifying end of life preferences (e.g. baptism, organ donation, autopsy, etc).
*** Offer the opportunity to re-discuss any information or changes in the clinical situation.** *** Maintain open communication.**	To acknowledge that parts of the care plan are hypothetical until the actual events occur. To respond to changing medical and psychosocial needs.