Neonatal Ethics Teaching Program

Problem Based Learning in Ethics (PBLE)

Critically Ill Newborn in the NICU

Supervisor Guide

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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 question: "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) Supervisor should be familiar with required readings and additional references.
2) Review, in detail, the "Procedural Form: Critically Ill Newborn."
3) Be familiar with the case scenario by using all three *Guides*.
4) Review the *Standardized Patient's Guide*.

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)

Instructions for supervisors

How to run a Problem Based Learning in Ethics (PBLE)

A. INTRODUCTION

The supervisor has to:

1. Remind the audience that the session represents a safe learning environment where mistakes are allowed for learning purposes.
2. Clarify any of the trainees' questions/comments about the respective PBLE's references or Procedural Form(s).
3. Explain the specific details about interacting with the SP as outlined below.
4. Ask trainees to make note of their comments or questions as they are observing the interactions with the SP.

Overview of role-playing with the Standardized Patient

The role-playing will happen in parts. The supervisor will give instructions during the Introduction as per the 3 sections below:

1. **Preparing for the role-playing:**
   - Ask one or more trainees to play the role of the doctor. One will start the interview and the next one will complete or modify the ongoing interview according to the suggestions made within the group. They may rotate more than once during their respective part.

   Note: The trainee(s) participating will have the *Trainee Guide* in their hands so they have all necessary information to reasonably understand the context and speak to the parent(s). If needed, please refer to Appendix A of the *Trainee Guide*.

2. **Process during role-playing**:
   - The trainee role-playing the doctor will have 10-15 minutes to complete his/her part of the interview.
   - Specify that mistakes are allowed and that to forget some steps from the Procedural Form is normal.
   - Remind the audience that the supervisor has the right to interrupt the interview at any time if s/he sees that the trainee is stuck or if comments need to be made (i.e. a great teaching point is noted).
   - Remind the trainee that also s/he has the right to stop the role-play if s/he feels stuck or uncomfortable.

3. **Scenario set-up**
    1. Ask the trainee who will play the role of the doctor first to step out of the room.
    2. Prepare the hospital scene with pre-organized material (i.e. bed for mother, the cot for the baby mannequin, a chair etc.).
    3. Call the SP into the room and introduce him/her (in their acting role only) to the observing trainees.
    4. Call back the trainee and make him/her practice with the SP.

B. PRACTICE WITH THE STANDARDIZED PATIENT

During role-playing, the supervisor has to:

1. Keep the workshop on time.
2. Observe the performance of the trainee.
3. Interrupt the interaction with the SP as required (see below).
4. Maximize interaction time with the SP (i.e. keep debriefing succinct).

When the scenario is interrupted, the supervisor has to:

1. Ask the SP to leave the room.
2. Proceed with debriefing the trainee who has played the doctor role by asking him/her what part(s) of the experience were easiest, followed by those that were most difficult. For example,"Can you identify one thing you did well?" and "Please, tell me, one thing that you would like to improve next time."
3. Clarify the difficulties or conflict encountered.
4. Reinforce strengths.
5. Generate a round table by asking some of the trainees who observed the interview to comment on one specific positive aspect and one aspect to improve.
6. Reformulate the comments that were not clear enough.
7. Ask the trainee who has played the role of the doctor to summarize at least one of the positive comments and one of the aspects to improve.
8. At the end, generate 2-3 options that the trainee can try for the next part of the interview in order to help resolve the difficulties or conflict.

After the debriefing, the supervisor has to:

1. Coach the trainee through the next part of the scenario.
2. Clarify with the trainee if he/she is comfortable applying the options.
3. Identify the moment of the interview where the SP has to replay the consultation.
4. Direct the SP outside the teaching room where he/she has to restart the interview and if he/she needs to make modifications to his/her role-playing.
5. Invite the SP to come back in the room and restart the scenario.

C. CONCLUSION

The supervisor has to:

1. Ask the SP to present his/her true identity and reveal their real personality to the trainees.
2. Ask for the SP's feedback to help the trainees either by identifying strengths or areas needing improvement.
3. Ask the trainees if they have questions for the SP.
4. Complete and summarize the workshop by asking all workshop trainees, including those who did not interact with the SP, to:
    - Review what strengths and learning points they remember and plan to take away with them.
    - Ask trainees to complete one electronic self-reflection form in the 24-48 hours after the workshop in order to assist their learning.
    - Remind them also to fill out the electronic self-reflection forms after real life situations.
5. Thank the SP and the trainees for their precious input.

Appendix A

Case Scenario with the Standardized Patient

MEETING #1

Imagine that the whole multi-disciplinary team has been putting in extreme efforts to provide optimal intensive care for Leona. Everyone is sad about the devastating start to life that Leona has experienced. There have been several other babies with HIE in the past 6 months, but Leona's case certainly appears to be the most serious.

Leona's mom, Mrs. Helen Richards, has just completed her first visit with Leona and the bedside nurse. Helen did not say much at the bedside; she appears to understand that things are not going well. She understands she is about to get a clinical update from the doctor for the first time.

When you call the trainee into the staged room, you tell him/her that the mom, Helen, is expecting to have the first clinical update on Leona's condition.

Note: If needed, refer to Appendix A of the *Trainee Guide*.

MEETING #2

Note: you will be required to give the trainee some additional written case information (see page 9). BRING COPIES for distribution.

Imagine that Leona's condition is largely unchanged at 48 hours of age. All team members remain concerned about her long-term neurodevelopmental outcome. Leona's mom, Helen, remains without her husband as he is stuck overseas. The team is hoping that Helen will have spoken with him about possible care plan options given the concern for Leona's outcome.

You now tell the trainee that he/she is about to re-meet Helen after having reviewed the "**NICU Progress Note #2**" (see following page). This meeting was planned after her previous visit to see Leona. **The trainee's role** is to provide Helen with a clinical update and proceed with the shared decision making process around Leona's care plan.

The information below is provided on paper to the trainees at the appropriate time DURING the PBLE. BRING COPIES for distribution.

NICU Progress Note #2

48 hour old term baby girl under therapeutic hypothermia for severe HIE (Sarnat 3). Birth weight 3.1 kg → current weight 3.4 kg

Issues:
1. Severe HIE – Sarnat 3 with seizures
2. Intubated and ventilated (secondary to initial apnea)
3. Oliguria with hyponatremia
4. Transaminitis

Status – by System:
- CNS: Therapeutic hypothermia continues
  - Neurology's impression: "Prognosis is guarded"; EEG done (results pending)
  - aEEG shows burst suppression pattern with occasional 'flat' periods
  - Leona had abnormal mov'ts at 36 hrs of age → Phenobarbital ½ load x 1
  - O/E: no spontaneous movement, no response to painful stimuli, pupils slightly unequal and sluggish, DTRs difficult to elicit but can elicit >10 beat clonus in upper extremities at the bicep tendon, intermittent hypertonia but predominantly flaccid tone, no suck/gag/Moro
- Resp: Still minimal vent support – 25% FiO2 and Leona is breathing above the rate
  - Stable blood gases
- CVS: No change
- GI: No further episodes of bright red blood per rectum; NPO
  - AST, ALT decreasing
- GU: Urine output ~0.8 ml/kg/hr over last 8 hours → baby remains puffy
  - TFI 40, D10/0.45NS with Ca/K; Labs: Na 131, K 4.4, BUN 8.1, Cr 147
- ID: Off Abx as C&S was negative
- Heme: Normal coags and CBC
- Metabolics: Lactate = 3.4; Glucose normal

Impression/Plan: Severe HIE with no improvement → worsening?. Continue current management. Consider arranging MRI of the brain. Meet with parents today to discuss current status and plans, including possible palliative care (?).

Appendix B

Clinical Information

- HIE outcomes (based on meta-analysis from *BMJ* 2010;340:c363):
    i. Sarnat 3 without cooling: 70% die or have a moderate to severe neurodevelopmental impairment at 18-24 months.

    ii. Sarnat 3 with cooling: 61% die or have moderate to severe neurodevelopmental impairment at 18-24 months.

    iii. For babies with Sarnat 3, there is only a trend towards a better outcome if they are cooled (i.e. it does not reach statistical significance).

- HIE prognostic factors in 'cooled' babies:
    i. Abnormal aEEG trace which does not improve by 48 hours in cooled babies is uniformly associated with a poor outcome (death or 1 or more of MDI <70, GMFCS 3-5, or no useful vision) (n=43) (*Pediatrics* 2010;126(1):e131-9).

    ii. Apgars of 0, 1, or 2 at 10 mins (without knowing the 1 and 5 minute Apgars) are associated with an 80% chance of death or moderate to severe neurodevelopmental impairment (n=51) (*Pediatrics* 2009;124:1619-26).

    iii. MRI of the brain may be useful for prognostication but notable limitations remain (*Pediatrics* 2010;126:e451-8). In infants with moderate HIE, conventional MRI in the first week of life has a sensitivity of 71% (95% confidence interval: 59%–91%) and specificity of 84% (95% confidence interval: 68%–93%) for very adverse outcomes.

- Therapeutic hypothermia can be stopped early if it is causing side effects or if it is considered unlikely to alter the outcome (as per all therapeutic hypothermia trials and protocols).

Appendix C
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.