



# Neonatal Ethics Teaching Program

## Scenario Oriented Learning in Ethics (SOLE)

### Antenatal Consultation at the Limit of Viability

#### Supervisor Guide

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## Description of SOLE

A SOLE teaches the principal and key 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 SOLE provides trainees the opportunity to practice and learn how they would interact with a true patient in a given clinical scenario. The goal is to help trainees show improvement in their communication skills and demonstrate appropriate application of ethical principles when they have to interact with parents in delicate, difficult, and ethically charged situations regarding their child. Trainees are encouraged to refer to a procedural form that outlines the steps they should follow during a one-on-one medical encounter and use the Standardized Patient (SP) as a teaching tool.

## Objectives

- 1) To improve communication skills when interacting with parents during an antenatal consultation for a mother at risk to give birth at the limit of viability
- 2) To identify areas of potential conflict at the limit of viability.
- 3) To explain the major ways to resolve conflict at the limit of viability.
- 4) To apply shared decision making principles when planning the management at the limit of viability.

## Required Reading

- 1) CPS Position Statement:  
<http://www.cps.ca/en/documents/position/management-anticipated-extremely-preterm-birth>

## Additional References

- 1) Yee WH. What information do parents want from the antenatal consultation? *Paediatr Child Health* 2007;12:191-196.
- 2) Boss RD, Hutton N, Sulpar LJ, Wes AM, Donohue PK. Values parents apply to decision making regarding delivery room resuscitation for high-risk newborns. *Pediatrics*;2008;122:583-589.
- 3) Kavanaugh K, Savage T, Kilpatrick S, Kimura R, Hershberger P. Life support decision for extremely premature infants: report of a pilot study. *Journal of Pediatric Nursing* 2005;20:347-359.
- 4) Young E, Tsai E, O'Riordan A. A qualitative study of predelivery counselling for extreme prematurity. *Paediatrics & Child Health* 2012;17:432-6.
- 5) Daboval T, Shidler S. Ethical framework for shared decision making in the neonatal intensive care unit: Communicative ethics. *Paediatrics & Child Health*; 2014;19:6:302-304.
- 6) See Appendix D for a list of references of guidelines from different countries on the perinatal management of extremely premature infants

**How to prepare for this SOLE**

- 1) Be familiar with required readings and additional references.
- 2) Review, in detail, the “Procedural Form: Antenatal Consultation.”
- 3) Be familiar with the case scenario.
- 4) Review the *Standardized Patient Guide* and *Trainee Guide*.
- 5) Meet with the SP one day prior to give instruction on scenario, reactions, and feedback.

## **SOLE Timeline**

### **Introduction (15 min)**

#### **Practice with the Standardized Patient (40 min)**

- 1) 25 min to cover the initial steps of the medical encounter.
- 2) 15 min of discussion.

#### **Practice with the Standardized Patient (40 min)**

- 1) 25 min to proceed accordingly through the medical encounter.
- 2) 5 min to cover the closure of the medical encounter.
- 3) 10 min of discussion.

### **Conclusion (20 min)**

## Instructions for supervisors

### How to run the Scenario Oriented Learning in Ethics (SOLE) Session

#### 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 SOLE'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. Identify the specific learner-centered goals to achieve for their part of the interview when interacting with the SP. 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 (time-in):

- The trainee role-playing the doctor will have 10-15 minutes to complete their part of the interview.
- Specify that mistakes are allowed and that to forget some steps from the Procedural Form is normal.
- Remind the trainee that they have the right to stop (time-out) the role-play if they feel stuck or uncomfortable.
- Remind the audience that the supervisor has the right to interrupt the interview (time-out) at any time if they see that the trainee is stuck or if unacceptable mistakes or behaviors have been made.

**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 them (in their acting role only) to the observing trainees.
4. As a last step, call back the trainee and make them 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 (time-out), 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 them what part(s) of the experience were easiest followed by those that were most difficult with the main goal to allow trainees to express their first reactions (reaction phase). 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. Provide feedback by reinforcing strengths (analysis phase).
4. Clarify the difficulties or conflict encountered to clarify the gaps (analysis phase).
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 (summary phase).
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 they are comfortable applying the options and achieve the next goals.
3. Make sure that the trainee is ready to go back in the scenario.
4. Identify the moment of the interview where the SP has to replay the consultation.
5. Direct the SP outside the teaching room to restart the interview and if they need to make modifications to their role-playing.

6. Invite the SP to come back in the room and return to the simulation (time-in

### **C. CONCLUSION**

#### **The supervisor has to:**

1. Ask the SP to present their 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.
5. Thank the SP and the trainees for their precious input.

## Appendix A

### **Case Scenario with the Standardized Patient**

You are part of the NICU team that received a consultation from Maternal Fetal Medicine (MFM) for a 27 years old mother in threatened preterm labor (TPTL) at 25 weeks and 4 days. Her pregnancy appears to be normal up to now, but she presented in hospital after she ruptured her membranes. Your attending neonatologist gives you the MFM consult sheet:

*“Please could you meet with this family and provide advice.*

*This mother is 27 years old, now at 25<sup>+4</sup> weeks GA, G<sub>2</sub>T<sub>0</sub>P<sub>1</sub>A<sub>0</sub>L1. She had a normal pregnancy and she is currently followed by MFM. US normal x 2. She has protective serology, but unknown GBS. Came in TPTL with ruptured membranes and dilated cervix.”*

**Note:** For additional information on the scenario, refer to the *Standardized Patient Guide* and Appendix A of the *Trainee Guide*. Note the potential different scenarios that may arise.

## Appendix B

### Clinical Information

1. Care can only be provided to a person if they consent to it (Ont. Health Care Consent Act 1996). In the situation of a newborn, the parents are the designated surrogates and they should act to protect the best interest of their infant. The surrogate has some obligation and should respect the wishes of the incompetent person, but if it is not known, they should act to protect their best interest. This is central in the decision making process.
2. There are two competing concepts used to define the best interest of the infant: “sanctity of life” and “quality of life.” The Canadian Pediatric Society (CPS) currently considers it to be in the best interest of the infant to resuscitate if it has over a 50% chance of survival without major complications. Nonetheless, approximately 15-30% of babies born at the limit of viability will develop long-term **severe** sequelae.
3. On one side, the physician has a professional obligation to respect the consent rights; and on the other, they are bound to their duties as mandated by professional guidelines.
4. According to the 2012 CPS position statement regarding caring for a woman who is at risk to deliver at the limit of viability, the physician will propose no life support intervention for a premature infant born at or less than 22 weeks gestation. At 23, 24 or 25 weeks’ GA, whether to provide intensive care should be individualized. At 23 and 24 weeks’ GA, active treatment is appropriate for some infants. At 25 weeks’ GA, CPS considers that active treatment is appropriate for these infants except when there are significant additional risk factors (e.g. hydrops, lethal congenital malformation, etc.). Keep in mind that it is a position statement and not an official guideline.
5. In fact some Canadian centers will offer palliative care at up to 25<sup>+6</sup> weeks’ GA if parents request it, even without additional negative prognostic factors.
6. If the parents are unwilling to consent to intensive care for a potential preterm infant  $\geq 26$  weeks’ GA (presuming no major risk factors for a poor outcome), the physician will have no choice but to act according to their professional duty and resuscitate the infant to protect its best interest. [Note: some physicians would argue that we have no choice but to resuscitate once the baby is  $\geq 25$  weeks’ GA (presuming no major risk factors for a poor outcome are present) we don’t know the right answer.] The physician cannot put themselves in jeopardy by not abiding by their professional duty. Under emergency situations (e.g. sudden birth of the infant), the physician could act without consent in this case as the infant’s life is in jeopardy. However, when the infant is medically stable, the case could be brought to Child Aid’s Society and the court of law in order to have a third party decide what should be done for their infant. The parents will have a chance to explain why they are asking for such a request.

## Appendix C

### Procedural Form: Key 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

#### ANTENATAL CONSULTATION

**Preparation:**

1. Identification of the reason for consultation and clarify the range of prognosis according to the expected gestational age prior to meeting with parents.
2. Review the maternal chart.
3. Discuss the plan with the obstetrical team (including fetal ultrasound result and estimated fetal weight).
4. Find a time and quiet place to make parents comfortable and allow for questions (30-60 minutes).
5. Try to have both parents present at the consultation (may need to schedule appointments). Appropriately inquire about the father's/partner's presence/absence (if applicable).

Steps	Further Explanation
<p>* <b>Welcome to parent(s) &amp; introduce yourself.</b></p> <p>* <b>Introduce other attendees as needed</b> (e.g. trainees, etc...).</p> <p>* <b>Welcome to others</b> (e.g. grandparents, acquaintances, etc ...) and inquire about the appropriateness of their presence in the room based on the parent(s)' wishes. Clarify their relationships to parents.</p>	<p>To establish trustful and supportive relationship and to introduce your role.</p> <p>To introduce others' role(s).</p> <p>To acknowledge that the situation is very sensitive and delicate and give the parents the opportunity to freely express their feelings or to have the support that they would like.</p>
<p>* <b>Inquire about the baby's name and refer to the baby's name.</b></p> <p>* <b>Understand and acknowledge the parent(s)' concerns.</b></p> <p>* <b>Be honest. Admit uncertainty when present.</b></p> <p>* <b>Maintain eye contact.</b></p> <p>* <b>Demonstrate compassion and empathy.</b></p> <p>* <b>Recognize the parent(s) wish.</b></p> <p><i>"I'm sorry to be meeting you in this difficult circumstance. However, I am here because there is a risk that [Name] may come early."</i></p>	<p>To show compassion and empathy by acknowledging that the situation is very sensitive and delicate.</p> <p>To establish a trustful relationship.</p>
<p>* <b>Introduce the agenda for the initial meeting.</b></p> <p>* <b>Use an open ended question to create the agenda according to the parent(s) needs.</b></p>	<p>To explain the specific steps during the interview.</p> <p>To reinforce the shared decision making process.</p>
<p>* <b>Build upon and evaluate the parent(s)' knowledge base, level of understanding, values, beliefs and preferences for participation in the decision making</b> by using an open ended question.</p> <p><i>"How I can help you to better understand the situation and to make plans for [Name]?"</i></p>	<p>To clarify if parent(s) have preferences or wishes as to what should be done for their infant in term of saving life, quality of life and suffering, since this will influence how you are going to discuss issues with them.</p> <p>To allow the parent(s) to "drive" the interview so you can go at their pace and level of understanding.</p>

Steps	Further Explanation
<p>* <b>Verify parent(s) perspectives</b> by using open-ended questions.</p> <p><i>"What is your experience with premature infants?"</i></p> <p><i>"What are your worries for [Name], if is going to be born in the next few days?"</i></p> <p><i>"How can I support you?"</i></p>	<p>To understand parents' perspectives and to be able to adjust what you are going to discuss accordingly to parents' worries, questions and needs.</p>
<p>* <b>Clarify incomplete components of medical and social history.</b></p> <p><i>"I reviewed your chart and I understand that... (Summarize briefly the information), but I would like to clarify some information..."</i></p>	<p>To gather information that could influence decision, prognosis, and care plan.</p>
<p>* <b>Transitional signal</b> toward discussion about consequences of prematurity</p> <p><i>"My goal in the next minutes is to share with you information that may help you understand the situation."</i></p> <p><i>"The information that I am going to discuss may be difficult to hear, but it takes into account your whole situation."</i></p>	<p>To prepare parent(s) about the information they will hear because it could be difficult for them to hear.</p>
<p>* <b>Share the information with parent(s) using short sentences and simple, non-medical terminology.</b></p> <p>* <b>Acknowledge our prognostic limitations and the limits of the meaning of statistics.</b></p> <p>* <b>Allow silence and time as often as needed.</b></p>	<p>To avoid long monologue and to allow parent(s) to integrate information.</p> <p>To use parent(s)' knowledge base, and respect the parents preferences about the type of information they wish to hear</p> <p>To ensure parent(s)' gain sufficient understanding about: survival, long term outcomes, short term complications and the hospital stay.</p>
<p>* <b>Evaluate parent(s)' understanding frequently and make readjustments as necessary. Offer time for parent(s) to ask questions as often as possible.</b></p> <p><i>"May I ask you to summarize what I told you?"</i></p> <p><i>"Is there anything else you need to know or understand better?"</i></p>	<p>To evaluate their understanding and competency for decision making and voluntarism (freedom to consent without undue third party influence).</p>
<p>* <b>Observe parent(s) reactions and listen to the way the parents describe the situation.</b></p> <p>* <b>If you can identify them, you can name them:</b></p> <p><i>i.e. Anger: "You seem upset by that ..."</i></p> <p>* <b>Acknowledge, validate and support parent(s) emotions.</b></p> <p><i>"Your emotions/reactions, are more than understandable"</i></p> <p>* <b>Allow them to keep some realistic hope (2 scenarios):</b></p> <p><i>"The days and weeks that you gain for [Name], will give them greater chances of survival and better long term outcome."</i></p> <p><i>"[Name] needs to be delivered early so they will have a better chance of survival and less of a chance to develop complications."</i></p> <p>* <b>Offer support to parent(s) all along the encounter.</b></p> <p><i>"We know that this is very difficult for you. Is there anything you would like me to do that would help you in a more concrete way?"</i></p> <p><i>"We will be with you all along the process...."</i></p>	<p>To acknowledge emotion by using general terms</p> <p>To demonstrate empathy by normalizing the reaction.</p> <p>To demonstrate empathy and acceptance of the parent(s) perspectives and concerns.</p> <p>To ensure that parent(s) do not feel abandoned.</p>

Steps	Further Explanation
<p><b>* Transition toward discussion about care plan.</b>  <i>"The news that I just shared with you is difficult to hear, but I need to discuss with you what can be offered to [Name] if they are born very soon."</i></p> <p><b>* Ask the parent(s) if they are comfortable with the current process or the way they are participating to the discussion.</b>  <i>"Are you comfortable to discuss now or would you prefer me to come back later?"</i></p>	<p>To prepare the parent(s) regarding their role in the decision-making if the baby is born.</p> <p>To make sure with the parent(s) that they are not too overwhelmed.</p>
<p><b>* Explain the usual care offered in that specific situation. Offer options according to the standard of care.</b></p> <p><b>* Always discuss options with parent(s) to allow them to participate.</b></p>	<p>To describe options based on the Canadian Pediatric Society statement.</p> <p>To increase their satisfaction in regards to participation in the decision making process.</p>
<p><b>* Offer a break time in order to give the parent(s) an opportunity to talk together and/or with other family members or friends and plan a follow-up meeting with them within 24 hours.</b></p>	<p>To allow the parent(s) to relieve some anxiety and decrease fatigue, so they will be able to take a step back in order to think about questions for clarification and thus make better decisions based on their own perceptions.</p>
<p><b>End of first meeting</b></p>	

<b>Follow-Up Meeting within 24 hours</b>	
<b>Steps</b>	<b>Further Explanation</b>
<p>* <b>Re-introduce yourself.</b></p> <p>* <b>Summarize previous discussion(s)/decisional care plan.</b></p> <p>* <b>Provide parent(s) the opportunity to ask any questions.</b></p>	<p>To ensure both parent(s) and medical team are at the same level of understanding.</p>
<p>* <b>Set the agenda for this meeting:</b></p> <p>Evaluate parent(s) preferences to participate in the decision making process.</p> <p>Negotiate a shared treatment plan for the care of the baby if s/he is going to be born.</p> <p><i>Use words such as: "team, shared, together" etc.</i></p>	<p>To emphasize the teamwork between parent(s) and medical team.</p> <p>To achieve the best management plan for the baby to which everyone agrees.</p>
<p>* <b>Based on the care plan decision, explain</b> what will happen to the baby in detail, including the usual behaviors of the baby, depending on the following care plan chosen:</p> <p><b>- Interventionist</b></p> <p><b>- Comfort care</b></p>	<p><b><i>In case of intensive care:</i></b> To help parent(s) understand what will happen to the baby after birth and explain that the father can follow the baby to the NICU.</p> <p><b><i>In case of palliative care:</i></b> To provide the opportunity to make sure that the parent(s) understand the decision by reviewing the dying process (if necessary). To be able to move towards clarifying end of life preferences as needed (e.g. baptism, organ donation, autopsy, etc.).</p>
<p>* <b>Obtain clear consent for the care plan.</b></p> <p><i>"Do you agree with the care plan that we made together for [Name] ...?"</i></p> <p>* <b>Empathize with parent(s) and their perspective while reaffirming care plan.</b></p> <p><i>"The decision we made is the best in the circumstances. We will make sure that [Name] ... will receive the care as we discussed."</i></p>	<p>To confirm the decision and ensure that they feel supported and secured.</p>
<p>* <b>Offer the opportunity to make any changes to the care plan now or later, recognizing there are limits.</b></p> <p>* <b>Offer the opportunity to re-discuss and information or changes of the clinical situation individually or with other supports (e.g. nurses, social work, etc.).</b></p> <p>* <b>Maintain open communication.</b></p>	<p>To acknowledge that parts of the care plan are hypothetical until the actual events occur.</p> <p>To respond to changing medical and psychosocial needs.</p> <p>To offer opportunities to be called at any time to re-visit them if they have any other questions.</p>
<p>* <b>Ask for any other questions or clarification before you leave.</b></p> <p><i>"Do you have any questions about what we have discussed today?"</i></p> <p>* <b>Close the interview by being appropriately hopeful.</b></p> <p><i>"Goodbye and we will see you again as needed."</i></p> <p><i>"We wish you the best and hope your pregnancy continues without further complications and that your baby does very well"</i></p> <p><i>"We will do our best, when [Name] is born and keep you informed at all times."</i></p>	<p>To ensure that the parents feel supported and secured.</p>

## Appendix D:

### List of references of guidelines from different countries on the perinatal management of extremely premature infants

#### USA

MacDonald H; American Academy of Pediatrics, Committee on Fetus and Newborn. Perinatal care at the threshold of viability. *Pediatrics*. 2002;110(5):1024 –1027

Batton DG and The Committee on Fetus and Newborn. Clinical Report-Antenatal Counseling Regarding Resuscitation at an Extremely Low Gestational Age. *Pediatrics* 2009;124:422-7

Committee on Fetus and Newborn. Noninitiation or Withdrawal of Intensive Care for High-Risk Newborns. *Pediatrics* 2007;119(2):401-403

#### UK and Britain

Nuffield Council on Bioethics. *Critical Care and Decisions in Fetal and Neonatal Medicine: Ethical Issues*. London, England: Nuffield Council on Bioethics; 2006. Available at: [www.nuffieldbioethics.org/go/ourwork/neonatal/introduction](http://www.nuffieldbioethics.org/go/ourwork/neonatal/introduction). Accessed January 7<sup>th</sup> 2015

Wilkinson AR, Ahluwalia J, Cole A, et al. The Management of Babies Born Extremely Preterm at Less than 26 Weeks of Gestation. A Framework for Clinical Practice at the Time of Birth. *Arch Dis Child Fetal Neonatal Ed*.

#### Italy

Verlato G, Gobber D, Drago D, Chiandetti L, Drigo P. Guidelines for Resuscitation in the Delivery Room of Extremely Preterm Infants. *J Child Neurol*. 2004;19(1):31-34.

Pignotti MS, Donzelli G. Perivable Babies: Italian Suggestions for the Ethical Debate. *J Matern Neonatal Med*. 2008;21(9):595-598.

#### Australasia and Australia

Womens Hospital of Australasia Clinical Practice Guidelines. Provision of Care to Mother and Fetus / Newborn at the Threshold of Neonatal Viability ( 22-25 weeks completed gestation ). 2005;(June).

Lui K, Bajuk B, Foster K, et al. Perinatal Care at the Borderlines of Viability: A Consensus Statement Based on a NSW and ACT Consensus Workshop. *Med J Aust*. 2006;185(9):495-500

#### Ireland

Neonatal Subcommittee of the Irish Faculty of Paediatrics. Statement on Perinatal Care at the Threshold of Viability. 2006.

**Switzerland**

Berger TM, Bernet V, El Alama S, et al. Perinatal Care at the Limit of Viability Between 22 and 26 Completed Weeks of Gestation in Switzerland. 2011 Revision of the Swiss Recommendations. Swiss Med Wkly. 2011;141:w13280.

Auckland District Health Board. Management of Pregnancies at Borderline Viability. Newborn Services Clinical Guideline. 2007. <http://www.adhb.govt.nz/newborn/Guidelines/Admission/BorderlineViability.htm>.

**Netherlands**

Verloove-Vanhorick SP. Management of the Neonate at the Limits of Viability: The Dutch Viewpoint. BJOG. 2006;113 Suppl3:13-16.