



Neonatal Ethics Teaching Program

Scenario Oriented Learning in Ethics (SOLE)

Unexpected Birth Malformation

Trainee Guide

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Description of SOLE

A SOLE teaches the principal and key competencies of the Neonatal Ethics Teaching Program that trainees 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 recognize the typical emotional reactions of parents to an unexpected birth malformation.
- 2) To describe ways to promote bonding between the parent and child.
- 3) To list at least three things parents want from physicians during disclosure of a birth malformation.

Required Reading

- 1) Drotar D et al. The adaptation of parents to the birth of an infant with a congenital malformation. *Pediatrics* 1975; 56: 710-7.
- 2) Janvier A, Watkins A. Medical interventions for children with trisomy 13 and 18: what is the value of a short disabled life? *Acta Paediatr.* 2013; 102: 1112-1117.

Additional References

- 1) Ryan S. Telling parents their child has severe congenital anomalies. *Postgrad Med J* 1995 71: 529-533.
- 2) Fallowfield L and Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004; 363: 312-19.
- 3) Baile W, Buckman et al. SPIKES-A Six-Step Protocol for Delivering Bad News: Application to the patient with cancer. *The Oncologist* 2000; 5(4): 302- 311.
- 4) Wilkinson DJC, Thiele P, Watkins A, and De Crespigny L. Fatally flawed? A review and ethical analysis of lethal congenital malformations. *BJOG* 2012; 119: 11: 1302-1308.

How to prepare for this SOLE

- 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: Unexpected Malformation at birth” (see Appendix B).

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)

Appendix A
Case Scenario with the Standardized Patient

NOTE:

You will learn about the specific malformation at the time of examining the baby mannequin at the workshop.

<p>Reason for consultation</p>	<p>You have been called by a nurse from the Labour and Delivery Ward as follows: “Please Doctor, come to Room 25. There is something wrong with the baby. We need you to deal with it!” You are given no other information and go right into the birthing room.</p> <p>As you enter in the room, you notice that the baby is isolated from the mom and comfortably wrapped up in a blanket. The baby is occasionally crying and is in no distress. The mother is on her own bed.</p> <p>Mom did not yet see or hold her baby. She does not even know if her baby is a boy or a girl. She has heard some crying. You can tell she is very anxious.</p>
<p>Role of the Trainee</p>	<p>Introduce yourself to the mother in order to get ready for disclosure of the news.</p> <p>After you examine the baby, please provide information to the mother and discuss options for care.</p> <p>Proceed with the shared decision-making process and make a plan for the care of the infant.</p>

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

UNEXPECTED BIRTH MALFORMATION
Preparation: <ol style="list-style-type: none"> 1. Identify the reason for consultation. If possible, clarify the range of possible diagnoses along with the prognosis of the unexpected malformation prior to meeting with parent(s). 2. Find a time and quiet place to make parent(s) comfortable and allow for questions (30-60 minutes). 3. 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
* Welcome to parents & introduce yourself.	To establish trustful relationship. Introduce your role.
* Encourage unknown people to leave the room (i.e. RN, acquaintances).	To give them the opportunity to freely express their feelings.
* Appropriately inquire about the father's/partner's presence/absence (if applicable).	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".
* Be sure that the baby is in the room with you.	To promote attachment to the baby.
* Refer to the baby with his/her name.	To acknowledge the baby, not the "disease".
* Look at the baby.	To promote mother-child bond attachment in a long-lasting relationship.
* Face-to-face interaction with parents.	To promote trustful relationship and at the same time indirectly reinforces the attachment to their baby.
* Make eye-contact with the parents.	
* Be honest and disclose the information by using simple words.	To allow the parents to "drive" the interview so that you can go at their pace and their level of understanding.
* Verify the level of understanding of the parents.	
* Provide the parents the opportunity to decide how they would like to hear the information about their baby. <i>"Do you want to see [Name]/your baby now, or talk first and then see your baby?"</i>	To give parents the choice of how to communicate. To promote attachment and bonding with the baby. NOTE: This depends on if the parents have seen the baby's malformation yet or not.

Steps	Further Explanation
<p>* After saying something nice and positive about her/their baby (If you did not do it before), your first statement about the malformation(s) should be bold and simple (using non-medical terminology), in short sentences that they are able to assimilate.</p> <p>1. "Unfortunately, I have unexpected news..." 2. " I think your baby has a missing arm/leg/hand/foot, etc." 3. "[Name]/Your child has a serious heart disorder."</p> <p>* Emphasize the normal aspects of the child (when applicable) and possible future positive possibilities if you are <u>sure</u> that the deficit is compatible with life. If not, <u>avoid</u> prediction about the child's future. Admit uncertainty while supporting parents.</p>	<p>To give warning that bad news is coming can decrease their shock. You need to select the information in order of priority (what is best to say first) using the parents' knowledge base.</p> <p>To ensure the parents keep some realistic hope.</p>
<p>* Ask before you tell. After the first brief informative phrase, you should continue by verifying the level of understanding of the parents as follows:</p> <p>"With regard to what I have told you so far..."</p> <p>1. "Have you previously been informed or do you have personal knowledge of the issues?" 2. "Is there anything you would like to understand better?" 3. "Is there anything you would like to know?" 4. "What is your understanding of what has happened so far?"</p>	<p>To reinforce a trustful relationship.</p> <p>Continues to allow parents to drive interview and reinforces their long-term trust on you.</p>
<p>* Observe parent(s)' reactions and listen to the way the individual describes the situation.</p>	<p>To identify the level of comprehension and emotional reaction (e.g. degree of denial).</p>
<p>* If you can identify them, you can name them:</p> <p><i>I.e. Anger: "You seem upset by that ..."</i></p>	<p>To be sensitive to the parents and normalize their reaction.</p>
<p>* Allow silence and time.</p> <p>* Evaluate parent(s)' understanding frequently and make readjustments as necessary. Offer time for parents to ask questions as often as possible.</p> <p><i>"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?"</i></p> <p><i>"After what I've told you, is there anything else you need to know or understand better?"</i></p>	<p>To ensure parents receive enough information to allow them to understand the magnitude of the issue.</p> <p>To empower the parent(s) to gain the information required for shared decision making.</p> <p>To, at any time and as often as possible, offer time for the parents to ask questions.</p>
<p>* Acknowledge and accept emotions from parents.</p> <p>1. "It is more than understandable that in this moment you have this reaction..." 2. "I can see this is hard for you and that you are upset. I am sorry; I wish the news was better."</p>	<p>To demonstrate empathy and acceptance.</p>

Steps	Further Explanation
<p>* Support parent(s)' emotions and feelings and allow them to keep some realistic hope.</p>	<p>To assist parents in having a better sense of their own involvement with the future of their child.</p>
<p>* Transition toward discussion about care plan.</p> <p><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 your baby. Is it okay to discuss this with you now or would you prefer me to come back later?"</i></p>	<p>To continue to reinforce the parental control of the interview.</p>
<p>* Explain the usual care offered in that specific situation. Offer support to parents.</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>To describe what can be done (investigations, consultations such as a geneticist or social worker, stepwise management plan including possible palliative care when appropriate).</p>
<p>* Ask parent(s) to make a summary of their overall understanding including the care plan options.</p>	<p>To evaluate parental understanding and competency for decision making (if there is one to be made).</p>
<p>* 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.</p>	<p>To ensure that the attention of the physician is not concentrated on what you want to make the parents understand, but on what they can understand, accept, and welcome.</p>
<p>* End making positive points about the discussion.</p> <p>* Offer secure net and encourage parents to keep track of questions for the follow-up encounter.</p>	<p>To reassure parents you are there for them and leave the door open for inquiry during a complex and difficult time.</p>

Appendix C: Standardized evaluation form for workshops and seminars

Evaluation Form Neonatal-Perinatal Rounds/Seminar

Please rate the characteristics of this rounds/seminar on the scale indicated

Presenter(s):							
Title:	Unacceptable	Needs Work	Fair	Good	Very Good	Excellent	Outstanding
Date:	1	2	3	4	5	6	7

<u>The Presenters</u>							
Enthusiasm							
Interaction with the audience							
Apparent knowledge of the topic							

<u>Presentation Style</u>							
Information was presented in an organized manner							
Used case-based methods; related information presented to practical problems							
Quality of audiovisuals							

<u>Content</u>							
Related content to current evidence in literature							
Content was relevant to your practice							

What aspects of this lecture did you like the most?

What aspects of this lecture would you suggest be changed in the future?

Overall, how would you rate this session?

1-Unacceptable 2-Needs Work 3-Fair 4-Good 5-Very Good 6- Excellent 7-Outstanding

Thank you for the feedback.