Neonatal Ethics Teaching Program

Scenario Oriented Learning in Ethics (SOLE)

Unexpected Birth Malformation

Supervisor 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) 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.
3) 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.

How to prepare for this SOLE

1) Supervisor should be familiar with required readings and additional references.
2) Review, in detail, the “Procedural Form: Unexpected Malformation at birth.”
3) Be familiar with the case scenario by using all three *Guides*.
4) Review the *Standardized Patient 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)

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 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 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 s/he sees that the trainee is stuck or if unacceptable mistakes or behaviours 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 him/her (in their acting role only) to the observing trainees.
    4. As a last step, 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 (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 him/her 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 he/she is 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 where he/she has to restart the interview and if he/she needs to make modifications to his/her 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 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.
5. Thank the SP and the trainees for their precious input.

Appendix A

Case Scenario with the Standardized Patient

Imagine that a nurse has been in the room for the delivery of this baby. The baby has been born, cried, and everything looked fine until he is brought under the warmer for newborn care. It is a baby boy and he is missing one whole leg. This must have been missed during the last ultrasound. The nurse feels uncomfortable and decides to call the physician in charge. On the phone she says: "Please doctor, come to L&D in Room 25 …there is something wrong with the baby, and we need you to deal with it!" (she wants the doctor to give mom the bad news). When the trainee enters the room, the nurse has already left the scene. The baby is in a cot, with his body wrapped up by a blanket. The mother is in her bed looking at the cot.

When you call the trainee into the staged room, you will tell him/her that mom has not seen the baby yet and is getting anxious.

Note: If the trainee asks you what the baby has, answer simply that s/he will know by examining the baby mannequin. **Please do not reveal any clue** about the baby missing his leg.

Appendix B

Clinical Information

- **Amelia** is the congenital absence of an arm or leg due to the interruption of the limb formation early in the embryo's development process (between 24 and 36 days following fertilization).
- An estimated one in 2,000 babies is born with all or part of a limb missing.
- Congenital absence of a limb is the least common form of amputation.
- Historically, there has occasionally been an increased number of babies born with limb defects or absent limbs (i.e. thalidomide use in pregnancy, U.S. defoliant used in Vietnam and radiation exposure in Chernobyl-Russia).
- Amelia can be caused by genetic factors, as sporadic, AD, AR and X-linked forms have been reported. Most of the time the cause of amelia is unknown.
- Amelia may be present as an isolated defect or associated with major malformations (i.e. cleft lip and/or palate, body wall defects, malformed head or brain, defects of the neural tube, kidneys, and diaphragm).
- Prognosis: A congenital limb absence has a profound effect on the life of the child and his or her parents. Children have been found to be extraordinarily good at learning to accomplish tasks and finding ways to compensate for their disability. Parents can help their child by encouraging persistence, allowing the child to do normal activities.
- Occupational therapy can help the child to learn how to accomplish complex tasks.
- Prosthetic devices are increasingly sophisticated. Some experts believe that early fitting of prosthesis enhances acceptance of the prosthesis by the child and parents.

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

UNEXPECTED BIRTH MALFORMATION
Preparation: 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). *** 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.** *** Be sure that the baby is in the room with you.**	To remove the element of the "unknown". 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.** *** Make eye-contact with the parents.** * **Be honest and disclose the information by using simple words.** *** Verify the level of understanding of the parents.**	To promote trustful relationship and at the same time indirectly reinforces the attachment to their baby. To allow the parents to "drive" the interview so that you can go at their pace and their level of understanding.
* **Provide the parents the opportunity to decide how they would like to hear the information about their baby.** *"Do you want to see [Name]/your baby now, or talk first and then see your baby?"*	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
*** 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.** *1. "Unfortunately, I have unexpected news..."* *2. "…I think [Name]/your baby has a missing leg."* *3. "[Name]/Your child has a serious heart disorder."* *** Emphasize the normal aspects of the child** (when applicable) and possible future positive possibilities if you are sure that the deficit is compatible with life. If not, avoid prediction about the child's future. Admit uncertainty while supporting parents.	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. To ensure the parents keep some realistic hope.
*** Ask before you tell. After the first brief informative phrase, you should continue by verifying the level of understanding of the parents as follows:** *"With regard to what I have told you so far…"* *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?"*	To reinforce a trustful relationship. Continues to allow parents to drive interview and reinforces their long-term trust on you.
*** Observe parent(s)' reactions and listen to the way the individual describes the situation.**	To identify the level of comprehension and emotional reaction (e.g. degree of denial).
*** If you can identify them, you can name them:** *I.e. Anger: "You seem upset by that …"*	To be sensitive to the parents and normalize their reaction.
*** Allow silence and time.** *** 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?"* *"After what I've told you, is there anything else you need to know or understand better?"*	To ensure parents receive enough information to allow them to understand the magnitude of the issue. To empower the parent(s) to gain the information required for shared decision making. To, at any time and as often as possible, offer time for the parents to ask questions.
*** Acknowledge and accept emotions from parents.** *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."*	To demonstrate empathy and acceptance.

Steps	Further Explanation
*** Support parent(s)' emotions and feelings and allow them to keep some realistic hope.**	To assist parents in having a better sense of their own involvement with the future of their child.
*** Transition toward discussion about care plan.** *"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?"*	To continue to reinforce the parental control of the interview.
*** Explain the usual care offered in that specific situation. Offer support to parents.** *"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?"*	To describe what can be done (investigations, consultations such as a geneticist or social worker, stepwise management plan including possible palliative care when appropriate).
*** Ask parent(s) to make a summary of their overall understanding including the care plan options.**	To evaluate parental understanding and competency for decision making (if there is one to be made).
*** 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.**	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.
*** End making positive points about the discussion.** *** Offer secure net and encourage parents to keep track of questions for the follow-up encounter.**	To reassure parents you are there for them and leave the door open for inquiry during a complex and difficult time.