



Neonatal Ethics Teaching Program

Scenario Oriented Learning in Ethics (SOLE)

Unexpected Birth Malformation

Standardized Patient Guide

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Purpose of the Guide

Dear Standardized Patient,

This guide is a tool for your preparatory training before your interaction with the trainees of our Neonatal Ethics Teaching Program. Prior to the Scenario Oriented Learning in Ethics (SOLE) workshop, you will participate in a 2-3 hour preparatory session with the SOLE supervisors (1-2 days prior to the workshop).

The purpose of this session is to ensure that your acting will recreate the history, personality/emotional state, and physical findings of the case to multiple trainees. We will also discuss the specific objectives of the script.

During the preparatory session, we will review the minimal competencies/behaviors expected from the trainees and the questions you will use to engage the trainees. To ensure trainees have a consistent experience, we will also review and practice body language and tone of voice (i.e. irritable, apathetic, fearful, etc.) as they related to the case. You will have the opportunity to ask any questions during this session.

The script contained in this guide focuses on the ability to communicate a bad news as an **unexpected malformation at birth**.

At the end of the SOLE workshop, you will have the opportunity to give verbal feedback to the trainees. Another purpose of the preparatory session is to remind you about how to provide constructive feedback to the trainees, knowing that you already have training in this area. Overall, you should verbalize feedback to the student from the perspective of the person you've portrayed by saying: "Chantal felt judged when you asked that question" and not "I felt judged when you asked that question." Your feedback will be summarized by the supervisors and will be distributed to the trainees shortly after the SOLE as a written document.

Lastly, we will do a short dry run of the case with you during this preparatory session. One of the supervisors will act as the trainee; s/he will ask you various questions and provide immediate feedback on verbal answers and body language.

Note: If needed, we will also ask you to sign a form consenting to be videotaped.

Enjoy!

Case scenario for Standardized Patient

Clothing for role-playing: Comfortable, loose clothes (e.g. 'sweat suit'); hospital gown (provided); you will be sitting in a chair and not too far from you will see a cot with a sleeping baby (mannequin) covered by a blanket.

Description for role-playing– SP will know all of this information:

You, Chantal, are a 32-year-old woman who arrived in Canada 6 months ago as a refugee from Rwanda (Africa). Soon after your arrival you realized that you were pregnant. This was your first pregnancy. The pregnancy went very well and you regularly saw a family physician here in Ottawa. During your pregnancy you found your situation hard because your husband had to stay behind in Africa for work and get his immigration paperwork organized. His documents were finally granted last week and he is coming to Canada tomorrow. Your husband will work for the Canadian Government. In Africa, you were working as a teacher in an elementary school. Since your arrival in Canada you've been at home. You do not have any family support (your family was decimated during the genocide), and you only have a few acquaintances where you live.

You wished all along to have your husband with you at the time of delivery, but you came to the hospital last night because you had contractions and your water broke. You had a normal pregnancy with no hypertension or known diabetes. You don't have any history of health problems. You didn't smoke or take any medication, alcohol, or drugs during this pregnancy. The fetal ultrasounds done earlier at the beginning of the second trimester, resulted normal without any notable malformations. Your GBS status was unknown but all your serological results (e.g. Hepatitis B, HIV, etc ...) so far are negative.

You had presented at 39+4 weeks gestation in active labor and, after 4 hours of contractions, you delivered vaginally about 20 minutes ago. It is 04:30 am and you heard your baby cry, but nobody is talking to you or bringing you the baby. You heard the nurse calling for a doctor. This doctor came and looked at your baby before leaving and calling for a more senior doctor. You still do not know if the baby is a boy or a girl. You are waiting from some sort of update from the medical team and wondering why nobody has been talking to you yet! The room was full of people you didn't know and they were all silent. They have just left the room. You feel confused and tearful. You realize that maybe there is something wrong with your baby! While you anxiously contemplate this possibility, the senior neonatologist (trainee) enters the room. You feel that something bad is going to happen.

Information to help role-playing:

- The doctor/trainee will deliver for the first time to you – the mother - the bad news of an unexpected newborn malformation, and the expectation is that s/he will proceed in steps as follows:

- Welcomes you and appropriately introduces him/herself to you.
- Appropriately enquires about the father's presence/absence.
- Asks you if you have seen the baby yet or not.
- Ensures that the baby is in the room with you.
- Encourages unknown people (i.e. RN, acquaintances) to leave the room.

1st SUGGESTED ATTITUDE. At this point if the doctor/trainee doesn't do these steps appropriately, you can pretend to be **angry** and start arguing with him/her as to why people do not talk to you, and what kind of secret they are holding from you!

- The doctor/trainee should warn you that the situation is delicate and not easy to take and, as an option, s/he could warn you that there is some unexpected news for you.
- **If the doctor/trainee doesn't do that step first, you still demonstrate anger and your feelings may even intensify.** You may ask: **"Why didn't anybody tell me as soon as they found out?"** (This step could be play-acted with other emotions including a shut-down attitude or sadness).

Note: We may need to stop the simulation for a 3-5 minute discussion if the trainee struggles. You will be asked to wait outside the room.

- There are different ways the doctor/trainee could interact with the baby and the parent(s) at this point even before starting the conversation. The recommended ways to approach the families that have not seen their infant yet are the following:
 - The doctor/trainee takes the baby in his/her arms and sits at the bedside to show you your baby.
 - Another way to do it is to take the small bed and put it closer to you, so you can start to see his/her face.
 - The doctor/trainee should also look at the baby while speaking.
 - In this specific situation, the doctor/trainee should tell you that your baby is a boy that is currently in good health, alive, breathing by himself, moving, etc.
 - The doctor/trainee should speak positively about your baby, but during the physical exam s/he noticed that there is a problem.
- The doctor/trainee should explain and offer you options about how you want to proceed in a face-to-face interaction (i.e. see the baby first, see the baby while s/he is talking to you, or talk first and then see the baby). "Would you like to see him first?" With this question, the doctor/trainee is giving you the option of how to guide the disclosure.

If you decide to see his body first and then talk about it, you can simply state your choice. Alternatively you may answer emotionally by saying that your son has been given to you, you love him, and you want to know "who" he is.

- At this point the doctor/trainee should take the blanket off the baby's body so you can see his malformation. You start to cry silently, while you hug and kiss your baby several times (**acceptance/bonding is happening**).
- The doctor/trainee should wait and leave you the space to express your surprise/emotion/crying/affection etc; by doing so s/he identifies your emotion and difficulties, by recognizing them as normal reactions (acknowledging them) offers you help to release your emotion and express it in a constructive manner.
- After acknowledging your distress s/he will appropriately and gently explain to you in simple words that the unexpected news is that your baby is missing a leg, but s/he appropriately tell you that your baby is otherwise healthy and breathing by himself, etc, s/he will then ask if you understood all the information that s/he has shared with you up to now.

Alternatively, **if you decide to listen to the doctor/trainee's explanation first**, before seeing the baby's body, you may simply state it by asking that you prefer to listen to his/her explanation first.

- The doctor/trainee should now share the information with you in a very simple, clear way in short sentences. This step could include the following interactions:
 - Allows you to 'take in' the information (allows silence and time).
 - Acknowledges your reactions (listens to you).
 - Accepts your emotions (which could range from plain denial and shock to taking responsibility for what happened).
 - Asks you for complementary information (i.e. if you have heard about the condition before, if there is anything you want to understand better, etc).
 - Shares information with you (only if you are ready to hear) about: short-term and long-term outcomes.
- The doctor/trainee should make the transition toward discussion about providing care for your baby by clearly explaining to you what kind of investigations s/he is planning to do for your baby now and in the next few days. During the interview, you can redirect the conversation and/or you may ask more questions if you feel that s/he did not clearly explain any of the following:
 - The nature of what was observed at the physical exam (i.e. **"How come this wasn't picked up during the antenatal ultrasound?"**);
 - What will happen to your baby now (i.e. **"Is my baby going to die?"** or **"What does he need?"**);
 - What the medical team is planning to do (i.e. **"Are they going to take my baby away from me?"**).

- The doctor/trainee should ask you, by using simple words during the whole conversation, if you understood all information that s/he has shared with you and should support your feelings and help you keep some realistic hope.

Note: We may need to stop the simulation for a 3-5 minute discussion if the trainee struggles with their response to these questions; you will be asked to wait outside the room.

2nd SUGGESTED ATTITUDE. If the doctor/trainee does not show you respect or empathy, if you do not feel supported, you may decide to “**shut down**”, stop listening, and enter into a **cold attitude** toward your own baby. You can use non verbal communication clues (i.e. avoid looking at your baby, avoid face-to-face interaction with the doctor, avoid holding your baby anymore, show indifference even in your answers. For example, when answering questions, if you decide to answer, use phrases such as: “Yah, sure”, “If you think so...”, “If you believe so”, or “As you wish”), or alternatively you can start crying.

- The doctor/trainee will soon realize that s/he is stuck in a situation with potential conflict, and that s/he will not be able to have your full attention/cooperation any longer.

Note: We may need to stop the simulation for a 3-5 minute discussion if the trainee struggles with this new situation s/he might ask to stop the session because needing feedback, emotional support or debriefing; you will be asked to wait outside the room.

3rd SUGGESTED ATTITUDE. If the doctor/trainee does not offer you a clear timeline for further investigations (such as head and abdominal ultrasounds) or consultations (genetics, occupational therapist, and/or others), you do not accept under any circumstances (indeed at this point of the conversation, you desire to have your spouse with you, you feel terribly alone, also the doctor/trainee doesn't seem to care about your particular circumstance).

- If the doctor/trainee has an attitude that is too paternalistic without explaining in simple terms the reasons of the investigations, your choice of tone on this matter can be altered and you may **ask forcefully** if these investigations could wait until your husband is present (which means waiting until tomorrow).
- In order to help share the decisions in regards to the care plan, the doctor/trainee should be open to your position and show some respect for what you are thinking and for what you want for your baby. For example: you wish to wait for your husband because you will need some time to speak with him **alone** – maybe before any investigations are done. You are open to collaboration but you do not understand enough if there is or is not urgency regarding tests and consultations.

- The doctor/trainee should acknowledge your desire and:
 - S/he should try to explain that certain investigations need to be done in **the best interests** of your baby, and you should expect the doctor/trainee to explain what that means and if there is an urgent matter to investigate.
 - Based on this information, you may reconsider your decision and consider going ahead with the investigations.
 - The doctor/trainee may also decide to respect your wishes for no investigations at this time or go ahead only with some investigations instead of all of them (i.e. the doctor is trying to compromise and support your wishes).

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 the Standardized Patient

1. At the beginning, you will not be introduced to the participants.
2. During the practice session with the trainees, you may be asked to leave the room and the scenario could be interrupted several times (time-out).
3. In the case of interruptions (time-out), the supervisor will speak with you again before resuming the session (time-in). The supervisor will advise you as to where to restart the interview and if you need to make any modifications to your role-playing.

Note:

- Repetition of certain sections is sometimes necessary for the trainees' learning experience.
 - The 'rotating' trainees may want to introduce themselves during the practice session even though they are supposed to be the same person in your eyes. Simply allow them to do so as this step makes them more comfortable.
4. At the end of the scenario, you will be introduced to the trainees and you will have the opportunity to tell them a little bit about your real self (i.e. your occupation and interests in life).
 5. You will listen to the review of the scenario's context, and then you will be asked to provide feedback about the strengths and potential areas for improvement to the trainees.

Thank you! We really appreciate your participation and valuable feedback!

Glossary of terms

GBS: Group B Streptococcus (GBS) is a type of bacterial infection that can be found in a pregnant woman's vagina or rectum. Those women who test positive for GBS are said to be colonized. A mother can pass GBS to her baby during delivery. Although GBS is rare in pregnant women, the outcome can be severe, and therefore physicians include testing as a routine part of prenatal care. The Centers for Disease Control and Prevention (CDC) has recommended routine screening for vaginal strep B for all pregnant women. This screening is performed between the 35th and 37th week of pregnancy (studies show that testing done within 5 weeks of delivery is the most accurate at predicting the GBS status at time of birth). The American Academy of Pediatrics recommends that all women who have risk factors **PRIOR** to being screened for GBS (for example, women who have preterm labor beginning prior to 37 completed weeks' gestation) be treated with IV antibiotics until their GBS status is established.

Serological tests: laboratory procedures carried out on a sample of blood serum, the clear liquid that separates from the blood when it is allowed to clot. The purpose of such a test is to detect serum antibodies or antibody-like substances that appear specifically in association with certain infectious diseases.