



# Neonatal Ethics Teaching Program

## Problem Based Learning in Ethics (PBLE)

### Unexpected Birth Malformation

#### Standardized Patient Guide

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## Case scenario for Standardized Patient

**Clothing for role-playing:** Comfortable, loose clothes (e.g. 'sweat suit'); hospital gown (provided).

### Description for role-playing

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 at 18 weeks were both normal and 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/resident will deliver the bad news of an unexpected newborn malformation, and the expectation is that s/he:
  - 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.

**Part A.** At this point if the doctor 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 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 difficult news for you.
- The doctor should identify your emotion or difficulties, and then recognizing them as normal, offer you help to release your emotion and express it in a constructive manner. **If the doctor doesn't do that step first, you still demonstrate anger and your feelings may even intensify.** (This step could be play-acted with other emotions including a shut-down attitude, sadness and others).
- There are different ways a doctor could interact with the baby and the parent(s) at this point. The recommended way to approach the families that have not seen their infant yet is for the neonatologist to take 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 should also look at the baby while speaking. In this specific situation, the doctor should tell you that your baby is a boy that is currently in good health, alive, breathing by himself, moving, etc. S/he speaks positively about your baby, but during the physical exam s/he noticed that there is a problem.
- The doctor/resident 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 is giving you the option of how to guide the disclosure. You say that your son has been given to you, you love him, and you want to know "who" he is. You decide to see his body first and then talk about it.
- At this point the doctor/resident 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**). You may say: "Why didn't anybody tell me as soon as they found out?"

**Part B.** If the doctor/resident does not show you respect or empathy you can decide to "**shut down**", stop listening, and enter into a **cold attitude** toward your own baby. You can use non verbal communication (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", "As you wish").

- The doctor 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.

**Note:** The doctor should ask you, 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.

During the interview at any time, you can ask the doctor: “Is my baby going to die?” and/or “What does he need?” 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; or, what the medical team is planning to do (i.e. “Are they going to take my baby away from me?”).

- The doctor 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.

**Part C.** If the doctor does not offer you a clear timeline for further investigations (such as head and abdominal ultrasounds) or consultations (genetics, occupational therapist, and/or others), or is too paternalistic without explaining in simple terms the reasons of the investigations, 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 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 if there is or is not any urgency regarding tests and consultations.
- The doctor 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 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 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).

## **PBLE 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 and the scenario could be interrupted several times.
3. In the case of interruptions, the supervisor will speak with you again before resuming the session. 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 to 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!