Neonatal Ethics Teaching Program

Scenario Oriented Learning in Ethics (SOLE)

Announcing the Diagnosis of Trisomy 21

Standardized Patient Guide

Authors

Boggs S, MD; Daboval T, MD, FRCPC; Ben Fadel N, MD, FRCPC;
Moore G, MD, FRCPC, FAAP; Ferretti E, MD, MSc, FRCPC.

Last revised: May 11, 2018

Table of Contents

Purpose of the Guide

Dear Standardized Patient,

This guide is a tool for your preparatory training before your interaction with the trainees of our Pediatrics and Neonatal Perinatal Medicine Program. Prior to the Scenario Oriented Learning in Ethics (SOLE) workshop, you will participate in an 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 relate 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 an unexpected diagnosis of **Trisomy 21.**

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 trainees from the perspective of the person you've portrayed by saying: "Amy 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!

SOLE Workshop Timeline

Introduction (15 min)

1) Pre-briefing between training and supervisor to outline workshop goals
2) Answering of questions to clarify the strategies for delivery of a diagnosis of T21 (trainees and supervisors)

Practice with the Standardized Patient (80 min)

1) 25 min to cover the initial steps of the medical encounter
2) 5 min to cover the closure of the medical encounter
3) 10 min of discussion

Conclusion (20 min)

1) Constructive feedback from standardized patient to trainees
2) Constructive feedback from supervisors
3) Debriefing to review the key learning points of the practice sessions

Program Evaluation (5 min)

Instructions for the Standardized Patient

1. At the beginning of the workshop, you will not be introduced to the participants.

2. During the practice session with the trainees, interruptions are allowed (i.e. time-out) initiated either by the trainee or the supervisor to allow for short debriefing and feedback. You will not initiate a time-out.

3. When the interruptions (time-out) are called, you may be asked to leave the room and the scenario could be interrupted several times.

4. 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.

5. Repetition of certain aspects of the encounter is sometimes necessary for the trainees' learning experience. If part of the scenario needs to be redone, you should proceed through the remainder of the encounter as if it is the first time you have done so.

6. At the end of the scenario, you will be introduced to the trainees partaking in the workshop and you will have the opportunity to tell them a little bit about your real self (i.e. your occupation and interests in life).

Note - The "rotating" trainees may want to introduce themselves to you 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.

7. 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. Please give the feedback from your character's point of view and give specific examples if possible as to what the trainee did well or areas they might work on.

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

Case Scenario for Standardized Patient

Clothing and setting 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 be a cot with a sleeping baby (mannequin) covered by a blanket. Alternatively, you may be sitting in a chair with the baby in your arms.

Description of standardize patient role

You, Amy, are a 28-year-old woman from Canada. This is your second pregnancy. You have had one miscarriage previously but the current pregnancy has gone smoothly and you are very excited about the birth of your first child.

You regularly saw your family physician here in Ottawa and feel you have a good rapport. You were offered routine prenatal testing but declined it as you had no specific concerns as your family history does not have any specific medical or genetic conditions that you know about. You had a brief period of spotting early in your first trimester and it never recurred. You have no history of 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 in the first trimester revealed a normal nuchal translucency measurement. The ultrasounds done at the beginning of the second trimester were similarly reported as 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 have been married for two years and your husband, Matt, has been supportive of your pregnancy. There has been some social stress as he works for the Canadian government and frequently travels for work. This will also be his first child and he is very excited about the event. He is otherwise healthy with no contributory medical or surgical history. He was adopted at birth and is not certain of his biological parents' medical history.

You came to the hospital last night because you had contractions and your water broke. You presented at $39^{+}4$ weeks gestation in active labor and, after 20 hours of contractions, you delivered vaginally without complications. You hear your baby cry and are overwhelmed with joy! The Obstetrician congratulates you and tells you that you have a new baby girl. After briefly holding her, the nurse brings your baby to a nearby isolette for routine care. You notice the nurse speaking in a hushed tone to the doctor who speaks quietly in return. You feel confused and worried about what is going and ask how your baby is doing. The nurse says she is doing well. Your daughter is bundled in her blanket and brought to you. You and your husband decided early on that if you had a girl you would name her Jasmine and you are pleased that it seems to suit her. You think she is beautiful but notice that she doesn't quite look like you or your husband. She keeps slipping down in your arms and you have to ask for help with readjusting your hold. You wonder why the doctor and nurse were

whispering to one another but block out the worry because you are so excited to finally meet your baby girl.

After you're all settled, your husband excuses himself with your visiting family to drive them home. A new doctor enters the room after they've left and introduces him/herself as the Pediatrician at the hospital. You suddenly feel anxious and wonder what they are here to talk about. You sense that something is about to happen.

Information to help with role-playing

- The doctor will deliver for the first time to you – the mother - the unexpected news of a Trisomy 21 (Down syndrome) diagnosis.

- There are different ways the doctor could interact with you and the baby while beginning the encounter but all approaches should include the following initial components:
  - The doctor should introduce him/herself and encourage unknown or additional people (i.e. RN, acquaintances) to leave the room.
  - They should inquire about your husband and clarify where he is as well as when he will be back.
  - The doctor should ask whether you would like to hold the baby during your conversation together.
    - If you decline, the doctor should place the baby in the small bed and put it close to you so you can still see her face.
  - The doctor should periodically look at the baby while speaking.

- To open the encounter, the doctor should speak positively about your baby and may congratulate you on the birth of your daughter.
  - If words of a particularly negative connotation are used at any point during the encounter to describe your daughter or the diagnosis this should be pointed out during the feedback period.

- The doctor should ask whether you have noticed anything "unexpected" about your baby and may use this as a tool to transition towards delivering the news.
  - You should respond to this by saying that you have found that your baby seems to have difficulty staying in one position in your arms and that she does not really look like your or your husband.
    - The doctor should validate these concerns and comment on other differences noted in general terms with specific elaboration on any particular features you inquire about.

- Prior to delivering the diagnosis of Trisomy 21, the doctor should provide a "warning sign" that alerts you to the fact that they may break some unexpected news.
  - Appropriate phrasing may include pointing out specific features in your baby that are common to Trisomy 21 or the use of terms such as "difficult" or "unexpected".

- The news should not be framed as "bad" and if it is this should be communicated during the feedback period.

- The doctor should specify that they are concerned that your baby has Trisomy 21 and ask what you know about this diagnosis.
  - An appropriate response is that you have worked with children with Down syndrome as well, as special learning needs as a teacher, but that none of your relatives or friends have been diagnosed with Trisomy 21 nor have they ever had a child with it.

- The doctor should identify specific physical features of Trisomy 21 that they see in your baby and define the cause of the syndrome using simple and straightforward terms.

- The doctor should explain the risk factors for Trisomy 21 and, if prompted, clarify why the diagnosis was not detected prenatally.
  - The doctor should not place any undue blame on the family physician even if prompted by you about whether your "family doctor did something wrong?"

- As you listen to the doctor's concern, you may continue through the encounter using one of the suggested attitudes outlined below.

1st SUGGESTED ATTITUDE: Anxious and Expressive

- As the doctor starts to deliver the news, you may begin to become **highly anxious**

- You may express your worries through a series of questions and ask about why this happened to you, why all of the ultrasounds during the pregnancy were normal, etc.

- As the trainee attempts to answer your questions, you may continue to interrupt him/her new and additional questions without waiting to hear the appropriate answers

- As your anxiety intensifies, this may be playacted with crying, yelling, or shutting down

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

2nd SUGGESTED ATTITUDE: Cooperative

- If the doctor has demonstrated strong initial communication skills (i.e. clear introduction of their role, positive opening statement, established quiet and supportive environment), you may choose to remain **receptive and cooperative** to the discussion
- At this point, you may start to **focus on your daughter** and cry silently while you hug and kiss her several times (acceptance/bonding is happening) without seeming overly upset or distressed by the news
- Alternatively, you may simply remain pleasant and attentive with open body language and no strongly expressed worries or negative emotions

3rd SUGGESTED ATTITUDE: Shut Down and Detached

- As part of this attitude, you should appear **"shut down"** and maintain a **cold demeanor** both toward the trainee and your baby
- You should 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) to demonstrate that you are no longer cooperative to the interview
- If you continue to answer questions, you should use short phrases that are difficult to elaborate on such as: "yeah, sure", "if you think so…", or "okay"
- The doctor 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; you will be asked to wait outside the room.

4th SUGGESTED ATTITUDE: Confrontational

- As part of this attitude, you may become very **upset and aggravated** by the news and openly express your frustration with rhetorical questions (i.e. **"why did this happen to me?**")

- You may begin to **raise your voice** and state that you don't wish to proceed with the conversation until your spouse returns or comment that that the doctor doesn't seem to care about your particular circumstance

- Alternatively, you may become more **antagonistic** and begin to ask more assertive questions such as "**are you going to take my baby away from me?**" or "**are you saying that my baby is going to die?**"

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

- Regardless of the attitude expressed, the doctor should wait in the room and give you time to express your surprise/emotion/crying/affection etc.
  - If you are visibly upset, the doctor may acknowledge your distress (ex. "I can understand if this comes as a shock").
  - The doctor may also choose to silently provide you with tissues or offer support if appropriate (ex. placing their hand on your hand).
  - If you feel hurried or pressured to continue the conversation, this should be communicated during feedback.

- As you react to the news, the trainee should display the following communication skills:
  - Allows you time to 'take in' the information which may include short periods of silence if appropriate.
  - Acknowledges your reactions and validates your emotions which could range from plain denial and shock to taking responsibility for what happened (ex. "it's natural to be overwhelmed").
  - Inquires as to what you would like to discuss first and shares information in a way that is tangible.

- The doctor should routinely pause to ask if there is anything they can help to clarify for you and invite any further questions you have thought of.
  - If you feel that something was not clearly explained, you may redirect the conversation to address it again.

- After explaining the diagnosis, the doctor should transition toward a discussion about what care will be provided for your baby.

- Again the doctor should clearly explain what kind of investigations s/he is planning (ex. blood work, echocardiogram, etc.) and offer a clear timeline for what will be done over the next few days.

- In order to help promote shared decision making in regards to the care plan, the doctor should be open to your position and show respect for what you think and want for your baby.
    - If at any point the doctor has an attitude that is too paternalistic or s/he does not explain in simple terms why the investigations are necessary, this should be communicated during the feedback period.

- If you express that you wish to wait for your husband because you will need some time to speak with him **alone** before any investigations are done, 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).
    - S/he might offer support by asking: "Would you like for me to be present when you will talk about Jasmine's condition to your husband?"

- The encounter should conclude with a summary of the plan as well as an effort to establish a follow-up time later that day or in the next few days for further discussion.

- The doctor may encourage you to write down your questions and offer to return when your husband is back to review the entire conversation with both of you.

Glossary of terms

GBS: Group B Streptococcus (GBS) is a type of bacteria that can be found in a woman's vagina or rectum. Although GBS has no impact on the mother, it can be passed to her baby during delivery and increases the risk of early infection. Routine screening is recommended for all pregnant women between the 35-37 weeks of gestation as 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 (ex. 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.

Routine prenatal testing: consists of both blood work and ultrasound screening. They should be offered to all women who become pregnant regardless of age. Additional diagnostic tests (i.e. amniocentesis and chorionic villi sampling) specifically indicated for all interested women 35 years of age or older, with risk factors in current pregnancy (i.e. abnormal screening test or ultrasound), or red flags in family history (ex. consanguinity, three or more spontaneous abortions, family history of chromosomal/genetic/birth defects, or previous pregnancy with chromosomal anomaly or genetic disease).

- *The first trimester screen (FTS)* is done at 11-14 weeks of GA and provides a risk estimate for Trisomy 21. It consists of two blood tests known as β-HCG and PAPP-A in conjunction with a measurement down on ultrasound known as nuchal translucency.
- *Nuchal translucency* measures the amount of fluid behind the neck of the fetus with measurements that exceed the normal limits indicating an increased risk of Down syndrome. When combined with maternal age, FTS has a sensitivity of approximately 85% with a false positive rate of 5%. Mothers with a positive FTS screen should be offered diagnostic testing in the form of chorionic villi sampling or amniocentesis.
- *The maternal serum screen (MSS)* is done between 15-20 weeks GA and can function as independent screening tool for Trisomy 21, Trisomy 18, and open neural tube defects. It may be offered alone if mothers missed the time window for an FTS or integrated prenatal screen (IPS). An MSS consists of blood tests that look at the levels of: maternal serum alpha fetal protein; β-HCG; and μE3. It has a sensitivity of 65% for T21 with a false positive rate of 8%.
- *The integrated prenatal screen (IPS)* combines the FTS and MSS. During the MSS, a blood test called inhibin A is also done. IPS has a sensitivity of 85-90% with a 2% false positive rate.

Trisomy 21, also known as Down syndrome, is the most common chromosomal abnormality. It is estimated to occur in 1/600 to 1/800 live births. The risk of T21 increases with advancing maternal age from 1/1500 at 20 years old to 1/20 by age 45 years. Despite this, given the natural history of when women tend to have children, the majority of children with T21 are still born to mothers younger than 30 years old.

Spotting: breakthrough bleeding that occurs early in pregnancy. Most often related to implantation of the fetus in the uterine wall but can be due to other more worrisome causes.