
Neonatal Ethics Teaching Program - Scenario-Oriented Learning in Ethics: Announcing the Diagnosis of Trisomy 21

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Abstract

Introduction: Delivering unexpected news to families can lead to emotionally charged conversations that cause discomfort and feelings of ineffectiveness in pediatric postgraduate trainees. Although prenatal screening exists, over 80% of trisomy 21 diagnoses continue to be made postnatally to unsuspecting parents who report a desire for better communication from health care professionals when they first receive the news of their child's diagnosis. Recognizing this area for improvement as reported in the literature, as well as the expressed desire from fellows in the University of Ottawa neonatal-perinatal medicine program for additional protected time to preemptively practice such disclosures, this trisomy 21 Scenario-Oriented Learning in Ethics workshop was developed. **Methods:** During the workshop, trainees are introduced to an evidence-based communication framework that provides them with strategies to facilitate clear knowledge translation and promote rapport with families for this specific clinical scenario. Participants are divided into small groups and practice disclosing a trisomy 21 diagnosis to a standardized patient in the role of a new mother. Each small group is supported by two trained facilitators who are experts in delivering life-altering news. **Results:** The pilot workshop was completed by 21 postgraduate trainees from the University of Ottawa. Qualitative evaluations were overwhelmingly positive, with feedback indicating high levels of perceived usefulness for the workshop. **Discussion:** By preemptively practicing evidence-based communication, we hope to increase trainee confidence and preparation for trisomy 21 disclosures and improve parents' feelings regarding the quality of communication and support provided while receiving real-life trisomy 21 diagnoses.

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Introduction

Within their practice, pediatricians and pediatric subspecialists are often faced with challenging conversations with families that require initiating and facilitating discussions related to life-altering diagnoses and difficult prognoses. In the area of neonatology, physicians must disclose difficult news about a variety of topics, including unexpected genetic syndromes such as trisomy 21 (T21). Pediatric residents and fellows frequently identify these conversations as one of the most complicated and nuanced parts of their training.¹ Many of these sensitive discussions can lead to feelings of insecurity in physicians if they do not feel adequately prepared to partake in them. This insecurity can ultimately hinder their ability to develop parent-physician rapport because their negative self-attri-

butions act as a barrier to communicating in a thoughtful, clear, and open manner.

T21 is the most common chromosomal anomaly, affecting approximately one out of every 700 babies born in North America.²⁻⁴ Although prenatal screening exists, over 80% of T21 diagnoses continue to be made postnatally to unsuspecting parents. These parents report a desire for better communication from health care professionals when they first receive the news of their child's diagnosis.⁵ Specific literature reviews on T21 have shown that parents repeatedly recall negative experiences when hearing a diagnosis of Down syndrome applied to their child.⁶⁻⁹ Practice guidelines have been released for genetic counselors that, given the scope of their practice, place a strong focus on the genetic implications of such a diagnosis for families as well as methods of investigating prenatally and postnatally¹⁰; however, these guidelines do not address the many clinical issues physicians discuss with families or practical strategies for responding to the multitude of concerns and reactions parents express during what is typically an emotionally charged conversation.

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Feedback obtained via comments from both evaluations and in-person discussion with members of the University of Ottawa neonatal-perinatal medicine fellowship program indicated that trainees wished to have additional protected opportunities to practice communication skills specifically related to the delivery of life-altering news prior to having to do so in true clinical encounters.¹¹ In an effort to meet this expressed need, the Scenario-Oriented Learning in Ethics (SOLE) small-group workshop series using trained standardized patients (SPs) was adapted from Martineau's model^{12,13} to provide participants with hands-on experience practicing evidence-based strategies for carrying out difficult conversations in a supportive, simulated learning environment.

The T21 SOLE focuses on a specific clinical scenario where a practitioner must disclose a suspected T21 diagnosis to parents when it was not prenatally detected. Recognizing the effective role that simulated encounters have on improving trainee confidence, as well as the need explicitly expressed by neonatal-perinatal medicine trainees, the T21 SOLE workshop was designed with SPs to facilitate translation of theoretical communication strategies into practical skill development in our adult learners. Simulated encounters have been found to be an effective means of subjectively improving trainee confidence related to the delivery of difficult news as well as objectively improving scores on measures performed by external evaluators.¹⁴⁻¹⁶ Small-group sessions with SPs have also been reported by participants to be useful and to promote improved preparation and flexibility for disclosures.¹⁷ In addition to simulation-based learning, the philosophy of the T21 SOLE was founded on the education methods of experiential learning, relational learning, small-group workshops, and activities structured to promote self-reflection, as well as inclusion of the family perspective.¹⁸⁻²¹

In summary, by taking part in this workshop, trainees are given the opportunity to practice navigating through the challenging aspects of disclosing an unanticipated T21 diagnosis to a new mother. The SP scenario and reactions are designed to simulate as realistic an environment as possible. By having experienced facilitators supervising the small-group sessions, trainees receive additional support and direct assistance with problem-solving difficult components of communication.

Methods

For each of our key players (facilitator, trainee, and SP), we developed guidebooks to read in advance of the

Educational Objectives

By the end of this workshop, learners will be able to:

1. Inform families of a trisomy 21 diagnosis in a manner that is sensitive to their cultural, social, and religious backgrounds.
2. Recognize and validate a variety of emotional reactions, even if they are not shared.
3. Explain trisomy 21 to parents in a manner that is easy to understand and answers their questions.
4. Incorporate shared decision making into a focused evidence-based management plan.

workshop. Each guidebook provided relevant role-specific instructions (Appendix A for facilitators, Appendix B for trainees, and Appendix C for SPs). The SP and facilitator guidebooks provided them with a detailed description of the SP's character and the workshop case scenario, including a list of possible attitudes that they could use to respond to the trainee based on the style of communication displayed by the trainee. The rationale and evidence (Appendix D) for the communication framework (Appendix G) were provided for the facilitators and trainees to use during the role-playing scenario. Facilitators and trainees were also given a summary of possible responses to questions commonly encountered with families during a postnatal diagnosis of T21 as an additional tool (Appendix H). Lastly, all references incorporated into the guidebooks were provided to all key players (Appendix I). In summary, to receive a complete guidebook, the facilitator should be provided with Appendices A, D, E, F, G, H, and I; the trainee should receive Appendices B, D, E, G, H, and I; and the SP should be provided with Appendices C and F.

The incorporated communication framework was developed specifically for this workshop. It was founded on evidence-based strategies and stated parent preferences for how families wish to actually receive a new postnatal diagnosis of Down syndrome for their child. It was designed to optimize multiple domains of both verbal and nonverbal communication using appropriate preparation, critical knowledge translation, language choice, emotional validation and exploration, and responsiveness to family needs.⁸⁻¹⁰ The framework did not provide an exhaustive list of techniques that could be utilized to facilitate effective communication nor was it a prescriptive order for how an encounter should occur. By providing trainees with this information in advance, they were primed with the necessary knowledge they needed to feel prepared to overcome the

uncertainty that might have prevented them from initiating a T21 disclosure.

Workshop Structure

The SOLE workshop was designed to take approximately 3 hours, with the time line outlined in each of the key players' instructions. Each small group included two facilitators, four to six trainees, and an SP. To facilitate independent but parallel small-group sessions, individual rooms were allocated for each small group to carry out its practice disclosures. Rooms were selected to ensure enough physical space for each group to run the scenario while the remainder of trainees observed. Each small group received a mannequin that acted as the baby so that group members could engage in the encounter in as realistic a manner as possible. SPs able to plausibly take the role of a new mother were selected and were instructed to dress casually. The involved facilitators were chosen because they had significant experience leading and facilitating difficult conversations with families as part of their medical practice. They had also been trained in the art of debriefing as this played a critical role in the learning process of all trainees during the workshop.

Carrying out the T21 SOLE

The day of the workshop began with a short session-wide introduction where participants were given the chance to ask questions about the communication framework to reactivate and deepen their understanding of the evidence behind the suggested strategies. Trainees were then divided into small groups that worked independently from one another but utilized the same guiding principles and overall structure.

In the small groups, each trainee was given the opportunity to practice delivering a diagnosis of T21 to an SP trained in the role of a new mother. By practicing a disclosure, trainees gained insight into how they would interact with a true patient's family should they be faced with this clinical scenario in real life. Although SPs were trained in the same character role, we encouraged them to respond to verbal and nonverbal cues expressed by the disclosing trainee in a manner that was as authentic as possible to mirror the evolving, active, and reactive process of real-world communication.²¹ In doing so, trainees who physically took part in the T21 disclosure received direct feedback about the effects of their body language and word choices, while trainees observing the disclosure were exposed to a variety of different approaches

as well as multiple attitudes from the SP on which they could reflect.^{16,22}

If, at any point during the practice disclosure, the trainee delivering the news felt stuck or if a facilitator identified that the trainee was struggling, a time-out was called to provide a short break from the scenario and highlight a particular teaching point.^{16,17} In order to preemptively learn from any mistakes trainees might make, scenarios were not interrupted by facilitators at the first sign of trainee discomfort as participants were allowed to experience the uncertainty they would feel in similar real-life situations. Simultaneously, facilitators did not allow participants to struggle for a prolonged period of time as this would have promoted frustration that ultimately impaired trainee progression. Facilitators were also given the chance to interrupt practice encounters to highlight a particularly effective strategy if this was seen as promoting one of the highlighted communication objectives.

At the conclusion of the workshop (after all trainees had had a chance to practice delivering a T21 diagnosis), the participants were brought together once again for a formal session-wide debrief focusing on generating key takeaway conclusions that could be retained in future encounters.^{16,23} Debriefing has been found to promote critical thinking and personal growth in those involved as it allows them to analyze their own reactions, emotions, and underlying values; adjust aspects of their previously acquired knowledge to incorporate newfound skills; and reconcile any concerns that arise.^{24,25} It is critical that the debrief be conducted in a professional manner highlighting the value of all trainee experience and demonstrating equal respect to those involved.²⁶ The debriefing was driven by trainee contributions, although facilitators would periodically use guiding open-ended questions to highlight strong examples and strategies of communication.²⁷ This allowed participants to release any stress they had built up during the simulated disclosure by formally discussing shared experience of transference and countertransference as well as techniques for managing personal stress in emotionally charged conversations.^{28,29}

Results

The SOLE teaching tool has been integrated into the neonatal-perinatal medicine program fellowship program at the University of Ottawa. The T21 SOLE was deployed once to 21 trainees in the spring of 2016. Workshop evaluations from participants were overwhelmingly positive.

Qualitative feedback was received both individually and during the group debrief, with 100% of participants indicating that they would take part in the workshop again.

A common theme that emerged was that trainees enjoyed having protected time to practice encounters. During the session-wide debrief, trainees from the workshop agreed on several general principles that they felt were highly useful, including having to practice breaking concepts down into simpler principles for the SP in order to avoid medical jargon, responding to the SP's conveyed emotions rather than presuming how the SP felt, and incorporating silence as a tool to allow the SP to absorb information.

Individual trainees also indicated that they developed personal learning points such as the following:

- “I felt a difference in our rapport when I communicated with the SP by using her baby’s name.”
- “I realized it could be helpful to cue the SP to potentially challenging news by pausing, looking away, and then reconnecting with eye contact.”
- “It was interesting to feel my own reactions to other people’s disclosure styles as it made me more aware of how parents might feel.”

In terms of limitations of the workshop, one of the themes that emerged was that although the communication guide was designed to be as adaptable as possible, there were cultural, social, and religious differences in how individual families might wish to receive a T21 diagnosis that could not be fully accounted for by a single tool. Trainees also acknowledged that at times, it was challenging to put aside their own biases for how they themselves might like to receive the news and maintain calm, open demeanors if the SPs acted in a combative or disengaged manner.

Overall, trainees indicated that although some of them did not feel highly confident in their overall T21 disclosure skills at the completion of the workshop, they still felt markedly more comfortable than they had prior to participating. Facilitators indicated that they felt the workshop was high yield, was easy to carry out, and met the stated learning objectives, with trainees perceived to be engaged throughout. All facilitators felt the workshop had the potential to generalize to other trainee groups, including genetics residents, general pediatrics residents, and medical students. SPs reported that they felt comfortable with the level of detail and instruction provided for their role

and that the workshop incorporated their character and feedback appropriately during the debrief periods.

Discussion

Though initial workshop evaluations from trainees were positive, we continue to integrate additional trainee, facilitator, and outsider opinions. Ultimately, through this exposure, we hope to continue to improve trainee communication skills as well as objectively evaluate whether the workshop can improve the way in which residents disclose a T21 diagnosis to families, with the hope of optimizing parent experience and facilitating better early physician-parent rapport.

A limitation we have encountered is the lack of time trainees spend familiarizing themselves with the preparatory materials prior to completing the workshop; however, in our practice, they still benefit from the experiences of this session. Furthermore, though SOLE guidebooks are offered to help improve participant communication skills, they are missing a valid and reliable tool to assist clinician educators in objectively assessing trainee performance in regard to communication skills. Operationalizing a definition for what constitutes *improved communication* (i.e., demonstration of techniques in the communication framework, more positive rapport, increased trainee confidence with encounters, etc.) remains challenging in the world of medical education. Consequently, we are in the process of evaluating the neonatal-perinatal medicine ethics teaching program. One aspect we are evaluating is the development of a validated assessment tool, which could be used both to objectively assess the communication skills of participants who have completed the workshop and to further evaluate whether this SOLE workshop leads to a significant improvement in the uptake of evidence-based communication strategies. We are also in the process of carrying out further needs assessments to expand our SOLE workshop audience to include other disciplines outside of neonatal-perinatal medicine, such as general pediatrics residents, genetics residents and counselors, and medical students. In addition to the T21 workshop, we have three other SOLE workshops as part of our University of Ottawa neonatal-perinatal medicine ethics teaching program and published on MedEdPORTAL: the antenatal consultation at the limit of viability,³⁰ the critically ill newborn in the neonatal intensive care unit,³¹ and unexpected birth malformation.³² These SOLE workshops also aim to improve communication during alternate challenging conversations.

The format can easily be adapted to any challenging situation a medical professional may experience. The scenario, teaching points, references, and evidence-based communication framework could also be adapted to an alternate SP character role that similarly incorporates a disclosure of an unanticipated postnatal T21 diagnosis.

Keywords

Scenario-Oriented Learning, Ethics, Neonatal Perinatal Medicine, Communication, Standardized Patient, Trisomy 21, Down Syndrome

Appendices

- A. T21 Communication Guide Facilitator.pdf
- B. T21 Communication Guide Trainee.pdf
- C. T21 Communication Guide Standardized Patient.pdf
- D. Rationale for the Communication Framework.pdf
- E. Clinical Scenario and Goals of Encounter.pdf
- F. Case Scenario for the Standardized Patient.pdf
- G. Key Components for the Communication of a T21 Diagnosis.pdf
- H. Knowledge-Based Principles.pdf
- I. Resources.pdf

All appendices are considered an integral part of the peer-reviewed MedEdPORTAL publication. Please visit www.mededportal.org/publications/10575 to download these files.

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IRB/Human Subjects: This publication does not contain data obtained from human subjects research.

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