

Co-Creating Caring Science-Based Interprofessional Simulation Through the Living Experience

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Abstract: The purpose of this project was to co-design an interprofessional simulation grounded in caring science that emerged from the living experience of families whose children suffered from Tay-Sachs. Families met with faculty to share stories and to review and update drafts of the simulation. When the final draft was completed, the faculty demonstrated the simulation for families before introducing it to students. Students focused on empirical knowing to get through the simulation, the orders, medication administration, and could not find compassion because within their personal knowing they could not find courage.

Keywords: simulation; caring science; suffering; death; dying

The purpose of this project was to co-design an interprofessional simulation grounded in caring science that emerged from the living experience of families whose children suffered from Tay-Sachs. Members of the Mathew Forbes Romer Foundation along with other parents/grandparents shared their perceptions of how to influence nursing education in the care for children and families who were suffering from fatal children's genetic diseases of the brain and spinal cord such as Tay-Sachs. A simulation was co-created, implemented, and evaluated within the Developing Family course. This manuscript presents the living experience of this project.

Hearing The Call for Nursing

Family members (four parents and one grandparent) shared their stories with faculty members

about loving and caring for their children who had suffered from Tay-Sach's. As the faculty listened to their stories and learned more about the mission/vision of the Mathew Forbes Romer Foundation, they heard the call for Nursing, the family members' goal to influence the education of nursing students, specifically for compassionate and competent care.

Following the meeting with family members, the faculty met together to review and reflect upon what they heard, and what they were coming to know. The family members felt very strongly about the competence and compassion needed to care for these children at home and that perhaps the simulation should not be situated in the acute care setting. Given that the nurse needs to first understand what can happen in the acute care setting in order to know how to keep a child from

hospital admissions, the faculty decided that the first simulation needed to be in the acute care setting and a future second simulation would be in the home setting. They met with the families again to share the first draft explaining the rationale for the acute care setting. Family members listened very carefully, asked some questions, offered some additional input and agreed. The faculty made final tweaks to the simulation and were ready to pilot it with nursing students. As requested, the faculty met with the family members a third time to demonstrate the simulation.

Co-Creating a Simulation in Response to the Call

Since 1911, several vendors have produced successful materials and programs for simulated learning that have demonstrated to be an effective clinical teaching method particularly for those hands-on clinical experiences not available to students in the health care setting (Aebersold, 2018). Simulated learning is designed to fill the gaps of experiential learning in the clinical setting and increase competency for standard situations and skills. This simulation is unique, however, as it was co-created within a curriculum grounded in caring science in response to hearing the call for Nursing.

Prior to actually demonstrating the simulation, the faculty met with family members to describe how the students would do preparatory work before engaging in the simulation. As the faculty and family members moved toward the simulation room, everyone could see the 3-year-old child (high fidelity pediatric simulator) was resting with easy respirations. There was a hesitancy on the part of the family members to enter the room. One family member left prior to the simulation due to having a previously scheduled meeting. One parent cautiously moved to the side of the bed, placing her hands on the side rail; another family member stood at the foot of the bed and stated, "This is too real." The simulation coordinator began the simulation. When she initiated the seizure activity, one family member tightened her grip on the side rails; the other family member put both hands on her face stating again, "This is too real. We're reliving this". The faculty were not prepared for this reaction; upon reflection, they realized they acted like most students: "It's just a simulation, the patient isn't real." The faculty came to know then that it is the *living* experience and not only the lived experience.

Simulation Pre-Work

The simulation was co-created within a curriculum that is grounded in caring science and includes: (Mayeroff's (1971) ingredients of caring (knowing, alternating rhythms, patience, honesty, trust, humility, hope, courage), patterns of knowing: empirical, personal, ethical, aesthetics, emancipatory, spiritual, sociopolitical, unknowing (Barry et al., 2015; Boykin & Schoenhofer, 1993; Carper, 1978; Munhall, 1993; White, 1995; Willis & Leone-Sheehan, 2019), Roach's (1987/2002), six Cs (compassion, comportment, confidence, competence, commitment, conscience), and caring theories of nursing. The ingredients of caring, patterns of knowing and Roach's six Cs are embodied within the teaching/learning strategy called the Nursing Situation. The Nursing Situation is a story "from day-to-day practice defined as the shared lived experience in which caring between the nurse and the one nursed nurtures wholeness and well-being" (Barry et al., 2015, p. 3). Students are familiar with nursing situations especially within didactic courses.

The simulation was integrated in the Developing Family course with 114 second semester junior nursing students. The simulation pre-work presented a brief nursing situation:

This simulation focused on a 3-year-old pediatric patient with Tay-Sachs disease who came to the hospital in acute respiratory distress. The child was seen in the emergency department last night and is now on the pediatric floor receiving care.

Students are to review the pathophysiology, diagnostics, and complications of Tay-Sachs and who they would include on the interprofessional team to help care for this child. Additionally, using Boykin and Schoenhofer's theory (1993), they are to reflect on how they could gain trust and discover what matters most to the patient and family. Then applying Watson's unitary caring science (2020), students were asked what *caritas* processes would guide them in the care of this child and family.

Simulation

The students were given shift report from the night nurse, reviewed the physician orders and began their assessment with the child's mother at the bedside. The simulation is presented in the Appendix and Table 1 presents these orders.

TABLE 1. Physician Order Sheet

Patient: Smith, Jacob	DOB: 1/31/xx	Location:220-B
Allergies: NKDA, mold, dust, seasonalrx: rhinitis	MRN: 12345	FIN: 008123
Primary Care Provider: Emily Moore, MD	Diagnosis: Respiratory Distress Precautions: Contact/droplet (MRSA, RSV) and Seizure	
Nurse verify each individual order and sign name/date at end of order set. When indicated, each order is checked off and initialed once completed		
Time	Date	Orders
10:00	today	Admit to: Pediatrics Code Status: Full Code Dx: respiratory distress secondary to Tay Sachs Vital signs: see recent, weight 16.7 kg *Activity: Bed-fast; reposition patient every 2 hrs Diet: Continuous 40 mL/hour tube feeding via G-tube Jevity 1.2 cal, with 100 mL water bolus every 4 hours. Check residuals every 4 hours. If greater than 250 mL hold for 1 hour recheck. Contact provider if >or equal to 250 mL after second check Medications (routine): Keppra 250 mg bid via g-tube Albuterol 0.083% 2.5 mg per 3 mL nebulizer treatment every 4 hours PRN Medications: Tylenol 15 mg/kg every 6 hours PRN temp >100.4 peg tube Motrin 10 mg/kg every 4 hours PRN temp >100.4 peg tube Valium 0.3 mg/kg/dose, IVP, every 15–30 min up to max dose 6 mg for seizure activity and call provider Maintain O2 Saturation >94% Suction as needed Vital signs every 4 hours Braden scale/skin assessment every shift Chest Physiotherapy treatment every shift (R/T care) Consult: PT, dietary, Infectious Disease Labs, AM collect CBC, CMP
Time	Date	Initial/Signature/ Title
		Emily Moore MD

Note. Defined in Merriam-Webster.com. Retrieved February 16th 2021, from <https://www.merriam-webster.com/>.

During the assessment, the child started to have a seizure. The students had to implement seizure precautions and administer the anti-seizure medication, being present for both the child and the mother. Following the seizure, the physician

came to the bedside and calmly stated that it was perhaps time to think about putting a Do Not Resuscitate (DNR) order in place. The physician exits the room leaving the students to be with a very distraught mother. The mother turned to

TABLE 2. Debriefing

Debriefing Points	^a Reflection
What went well during the simulation?	
What could have gone better during the simulation?	
How did the family respond to you gaining trust and asking “what matters most?” How did you show presence? (Boykin & Schoenhofer, 1993)	
When the physician calmly stated that it was perhaps time to think about putting a DNR in place, what were you thinking and feeling at that time? What happened after that? How did you feel?	
Reflection on Caring	^a Reflection
Where did you see (Watson’s (2020) caritas processes utilized during the sim?	
Mayeroff’s Ingredients of Caring—awareness of self as caring person—how was this exhibited during the simulation?	
Who am I as a caring person? What was offered during the simulation?	

Note. Format of the debriefing document modified for publication.

^aReflective journaling is to include John’s (2017) model for structured reflection and Mayeroff’s (1971) Ingredients of Caring.

the students crying, “What does he mean a DNR order? Is he saying my son is going to die? Is he saying there is no hope?”

Student Reflection on The Simulation

Student debriefing and reflection revealed a rich coming-to-know experience (Table 2). Some students wanted to call someone else to be with the mother such as the chaplain or a social worker; they felt unprepared and did not know what to say or what to do. Many students had not yet had any personal experience with death and dying. This helps to explain how during the simulation, students focused on the physician orders, the tasks (i.e., medication administration), and how to “divvy up the care.” Exemplars of student reflection are presented within two repeating patterns: “I did not know what to say. I did not know what to do;” “The mother and how she was feeling was the furthest thing from my mind . . .”

“I did not know what to say. I did not know what to do.”

A time that my classmate and I moved well together was when the patient began to seize. It was a learning experience that helped us work together through emergency and stressful situations. And I felt confident. However, the patient’s mother began to become distressed and that is when we were thrown off-guard because for the most part our simulations do not allow us to encounter a grieving mother.

Another student wrote:

My classmate went on to time the seizure as I started getting the medication ready. At this point, I was feeling a bit tense and nervous because I kept forgetting small things here and there—which in real life wouldn’t be so small.

One other student wrote:

I failed to properly cosign the administration of a very toxic medication to our patient. Throughout the rest of the simulation, I could not get past the fact I could have potentially caused the death of my patient. This experience will be one I carry with me throughout my nursing career to remind me of the importance of proper medication administration.

When the physician left the room, we were extremely shocked and at a loss for words. Since I personally have never been in the position, I felt that in the essence of the simulation I didn’t know what to say or how to handle it.

“The mother and how she was feeling was the furthest thing from my mind. . .”

This simulation was placed within the Developing Family Course where the wholeness of family is studied: concepts and theories of family, human growth and development, health promotion, risk reduction, and disease management for nursing situations with childbearing women, children, and families are integrated. Following the debriefing, one student wrote that she realized the simulation “was a full circle experience of caring for the whole family.” However, students came to know how difficult it can be to care for the wholeness of family.

I felt so focused on caring for the patient that the mother and how she was feeling was the furthest thing from my mind . . .

My actions and those of my classmates negatively affected the mother who was in the room. We were so focused on caring for her son that we didn't even stop to think about how she was feeling as her son was going through all of this.

We were focusing on the child that we didn't verbalize to the mother what we were doing.

Discoveries/Reflections: Grounding Clinical Education in Caring Science

Following the simulation and during debriefing, students were asked to reflect on (Mayeroff's (1971) *Ingredients of Caring* with these questions: How was awareness of self as a caring person exhibited during the simulation? How did you offer who you are as caring person during the simulation? Exemplars of student writing are presented.

We failed at 'patience, honesty, and trust; courage;' every time the mother asked what we were doing, I rarely spoke up to explain. We should be able to communicate with the mother.

I did not know what to say. I did not know what to do. It takes courage to accomplish all the ingredients of caring.

Knowing what to say and what not say to someone in that state could help or hurt them tremendously in their remaining time at the hospital.

No student ever mentioned or referred to compassion.

Several students wanted to call someone else to be with the mother: the chaplain or the social worker. Other students referred to this as *their job as nurses* to console the mother and provide her with more information. Questions faculty need to ask and reflect upon include:

Do students understand the real role of the professional registered nurse?

How are faculty helping them to incorporate the ingredients of caring (Mayeroff, 1971), patterns of knowing (Barry et al., 2015; Boykin & Schoenhofer, 1993; Carper, 1978; Munhall,

1993; White, 1995; Willis & Leone-Sheehan, 2019), Roach's (1987/2002) 6 Cs, and anchoring their practice in a caring theory of Nursing such as Watson?

Is it possible to manifest Roach's (1987/2002) 6 Cs especially compassion without fully understanding the ingredients of caring and coming to know self as caring person first?

Students also expressed the value of experiencing this simulation.

So, I was lucky that I was able to go through the simulation in order to know how to act and what to say in case I do have to deal with a similar situation within the future.

Having been introduced to the possible situation and the likelihood of having this interaction in real life I believe has opened my eyes and prepared me for the future.

Given the COVID pandemic and Nurses on the front line, how are faculty preparing students to care for self in his/her wholeness and then for the very real here and now to provide competent, compassionate holistic care for persons who are experiencing suffering, grief, death, and dying? Regardless of the practice setting, in a pandemic, faculty need to help students understand that there is no "In case I have to deal with a similar situation" involving suffering, grief, death, and dying.

The Call for Compassion

The essence of this simulation that has emerged is how faculty need to show compassion for the students during and after the debriefing. When the student experiences compassion then perhaps it is possible for the student to attempt to experience what the patient or family member is experiencing and that the potential loss of someone they love is "the hardest thing possible" (Roach, 1987/2002, p. 45).

Upon review and reflection, faculty offer the following recommendations for ordering the debriefing points that may help students with their awareness of self as caring person:

1. Given the students' reaction to the simulation, the debriefing could begin with asking students what they were thinking and feeling when the physician stated that it was perhaps time to think about putting a DNR

- in place and then leaving the room. The faculty member may share his/her experience in a similar situation during nursing school.
2. Begin the reflection on caring through all Mayeroff's (1971) ingredients. Remember the students felt they "... failed at 'patience, honesty, and trust; courage.'"
 3. Review the patterns of knowing especially personal, ethical, spiritual, and unknowing. Share the patterns you as the faculty observed the students manifesting during the simulation. This may help with the students' feeling of confidence (Roach, 1987/2002).
 4. Now ask students to share which caritas processes were within the simulation.
 5. Finally, ask students what went really well and what could have gone better during the simulation.

Clinical education grounded in caring science whether it is via simulation or in the real clinical setting requires the experience and expertise of faculty to help students internalize the ingredients of caring, patterns of knowing, and Roach's 6 Cs that will provide them the foundation for a caring theory of nursing to guide their practice. As one student so beautifully wrote, "Learning how to handle a caring environment is one thing but learning how to handle an environment based on caring science is a whole new ball game. Watson's caring theory in its entirety was engulfed in this simulation."

Even within a curriculum grounded in caring science, student and faculty reflections helped in understanding and appreciating the importance to re-enforce (Mayeroff's (1971) ingredients of caring, patterns of knowing, Roach's (1987/2002) 6 Cs, and theory-guided practice not only in simulation but in all real or virtual clinical and classroom experiences. Additionally, faculty and students need support with coming to know self and other in his/her wholeness and caring for self as well as for each other, patient, and family during these difficult very real situations.

Future Directions

This simulation is unique as it emerged from the *living* experience. Perhaps this is why family members, faculty, and students were filled with raw emotion. Students focused on empirical knowing to get through the simulation, the orders, medication administration, and could not find compassion because within their personal knowing they could not find courage.

Prior to simulation, the pre-work might need to include reflection regarding personal knowing and/or experience with grief, death, and dying. Faculty need to review the undergraduate curriculum on where these end-of-life concepts are embedded and scaffolded throughout course content and clinical experiences. Clinical faculty may need support in how to guide students through suffering, death and dying witnessed at the bedside and now in the daily news regarding the pandemic.

The simulation needs to be expanded to include two more nursing situations. The second session could be an in-class role model/simulation where the nurse explores with Jacob's mother what she wants for her son and then bringing together an interprofessional team to plan discharge to home and home care for end-of-life. The final part of the simulation would be in the simulation lab. This would be caring for Jacob and his family at home. As the family members felt very strongly about the competence and compassion needed to care for these children at home, the faculty want to invite the family members to work together again to co-create a caring science-based simulation from the living experience.

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Appendix: Tay Sachs Pediatric Simulation©

Simulation Scenario Overview : Pediatric 5 year old with Acute Respiratory Distress / Tay Sachs Disease

Patient Name: Smith, Jacob
DOB: 1/31/XX 5 years
Allergies: NKDA
Height: 3' 10"
Weight: 16.7 kg

Estimated Pre Sim work discussion time: 20 min

Estimated Debrief Time: 30 min

Estimated Simulation Time: 20 min

Summary: This case presents with a 5-year-old that was admitted through the Emergency Department with moderate respiratory distress. Patient has a history of Tay Sachs.

The student will be expected to demonstrate the standard of care demonstrating competent, safe, holistic care for the patient and the family.

The student will be expected to provide appropriate assessment & treatment of the respiratory distress, and seizure activity as well as a holistic plan of care for a neuro-compromised patient.

In this scenario, a caring science focus will be on the patient and the family member present. The role of the student nurse is to build a trusting relationship for the care of the patient in this pediatric inpatient care setting.

Preparation for Sim Junior:

1. Acute Pediatric Hospital setting
2. Pediatric bed -extra pillow for turning
3. Provider order sheet
4. Vital sign equipment B/P, Temp, SPO2*electronic monitor if possible.
5. MAR (electronic)/Pyxis system for med.
6. Nebulizer (face mask)
7. Medications: Per order. Two medications that will be administered are Diazepam and Albuterol. Saline flush and bottle of Diazepam. Needles and syringes—students to find correct sizes.
8. Report sheet (given by night nurse)
9. IV site (Saline Lock connection, with reservoir)

Equipment Checklist:

- Droplet /Contact precautions—proper gown/gloves/mask
- Stethoscope—in isolation room
- SpO2 monitor/tympanic/B/P
- Oxygen supply N/C
- Suction in the room
- Kangaroo pump equipment in room as a prop—not used in this sim.
- Respiratory Nebulizer equipment (mask and nebulizer)

Student Nurse Participants:

- Primary RN
- Secondary RN
- RN—Medication Nurse
- RN—Interventionist

Learning Objectives:

1. Implements patient safety measures
2. Evaluates patient assessment information.
3. Prioritizing plan of care.
4. Implements holistic therapeutic communication.
5. Demonstrates effective teamwork and collaboration
6. Prioritizes provider orders appropriately.
7. Implements direct communication with family members and team members for optimal plan of care.
8. Establishes trust and authentic presence using caring based science approaches to patient and family care.

Scenario Specific Objectives:

1. Recognizes the signs and symptoms of respiratory distress (physical assessment and vital signs).
2. Recalls the indication for oxygen therapy, and need respiratory nebulizer treatment.
3. Initiates relevant respiratory monitoring.
4. Recognizes symptoms of seizure activity. Institutes seizure precautions in the care of the patient.
5. Recalls indications, contraindications and potential adverse effects of prescribed medications using the “8” rights of medication administration
6. Initiates therapeutic caring approach to family member after provider updates the parent on the prognosis and plan of care

Simulation	Monitor Settings:	Patient/Actions	Student Interventions	Cue/Prompt from Parent
Acute Pediatric Patient room				
5 minutes	Shift report give on Jacob to the morning nurses *Night nurse then becomes the mother of Jacob sitting next to him at the bedside.			
5 to 10 min	Initial State: HR: 105 BP: 110/90 SPO2: 88% RR: 25 Temp 99.1 F	Auscultation sounds: Lungs Wheezing Coarse Set simulator to "SOB" vocal Bed at Low Fowlers	Listen to mother's report of new onset Respiratory issues, and concerns with care. Gain trust with parent. Assess Lung sounds intervene with O2 N/C and high fowlers position. Nebulizer treatment initiated	"He seems short of breath." "We make sure our children and visitors do not visit Jacob at home when they have colds." "He has been doing so well for the past 6 months."
10 to 12 min	Respiratory distress Resolved		Lungs reassessed SPO2 assessed	
12 to 20 min	Seizure Activity: starts Discuss Care and concerns that the parents might have and discuss S/S of seizure activity	*Set Seizure activity—high magnitude tonic/clonic Students need to initiate seizure precautions turn Jacob on his side. Remember to time the seizure, and use something to pad the bed. Once diazepam has been given IV push, stop the seizure activity.	Provide Anti-seizure med (this may take a few minutes for the students to prepare) *Pre sim when students look up the medications, they are told that Diazepam is a high alert medication and requires two nurses to verify dose.	If students do not recognize seizure. Mom states "I think he is having a seizure." "He hasn't had a seizure for over 2 weeks. Do you think he is outgrowing his Keppra? He did gain 5 pounds over the last 2 months".
20 min–30 min	Provider arrives to discuss plan of care with mother. States that the chest x-ray does not look good. Jacob likely has pneumonia, and with increased respiratory effort will not be able to maintain breathing on his own. It has now come to a point of care where mechanical ventilation will be required if he should stop breathing. "We need to talk about DNR for code status" "Doctor states she needs to check on sputum culture results and will be back.	Student nurses are there to listen to mother. Clarify the MD plan of care. Offer support using caring theory.		Mother states to the Nurses "what does DNR mean?" "Jacob has been doing so well. We have been taking such good care of him." He hasn't been sick." Does this mean that they are giving up hope for Jacob? "Mother appears upset. She states "I don't know what I would do without Jacob" (Wringing hands, stroking Jacobs head) *Wait for students' response, and then end the simulation. Go right into debriefing.

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