



Pediatric End-of-life Simulation: Preparing the Future Nurse to Care for the Needs of the Child and Family

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ABSTRACT

Purpose: Preparing a future nurse to respond to the complex and sensitive needs of a child and family during the end-of-life requires more than didactic content in a classroom. During clinical experiences, students may care for children diagnosed with a terminal illness however; it is less likely that a student will have a clinical opportunity to care for a child and their family at the end-of-life. Without having an experience, it is challenging to teach students how to care for the dying child and family including how to appreciate the emotions, thoughts, and expectations when faced with a pediatric death (Lindsay, 2010).

Design and Methods: The instructional model integrates an end-of-life simulation into an undergraduate pediatric nursing course allowing students to practice caring for a child and their family while developing an understanding of the unique needs of a dying pediatric patient.

Results: Post simulation, students participating in guided reflection, identified several themes impacting their experience with end-of-life care, including symptom management, emotional care and “what to say”.

Conclusions: The structured simulated experience provided knowledge, skill and awareness to the role of the nurse when providing care at the end-of-life.

Practice Implications: Nurses' behaviors and responses when caring for a child can have a significant impact on the family's experience and memory of their child's death. Unintended actions may result in the family experiencing negative impressions, causing further distress to the grieving family (Butler, Hall, Willetts, & Copnell, 2015).

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Purpose

The Essentials for Baccalaureate Nursing Education state that the graduating nurse should possess knowledge, skills and attitudes to care for individuals across the lifespan including the young and vulnerable (AACN, 2008). One method to facilitate learning in nursing is the use of simulated experiences. The National League of Nursing (NLN) describes simulation as “an attempt to mimic essential aspects of a clinical simulation with the goal of understanding and managing the situation better when it occurs in actual clinical practice” (NLN, 2018).

Pediatric palliative and end-of-life care content may be covered in the didactic portion of nursing education but little information is available about the incorporation of a pediatric end-of-life simulation learning experience in nursing curricula. Student nurses, experiencing their first adult patient death in clinical, expressed emotional distress and feeling unprepared despite having didactic content in the academic

setting (Heise & Gilpin, 2016). During clinical experiences, students may care for children diagnosed with a terminal illness however; it is less likely that a student will have a clinical opportunity caring for a child and their family at the end-of-life. Without having an “experience”, it is challenging to teach students how to care for the dying child and family including how to appreciate the emotions, thoughts, and expectations when faced with a pediatric death (Lindsay, 2010).

Having the opportunity to practice how one would respond to challenging situations is important, especially when caring for sensitive cases. Nurses' behaviors and responses when caring for a child can have a significant impact on the family's experience and memory of their child's death (Cantro, Larson, Scofield, Sourkes, & Cohen, 2004). Unintended actions may result in the family experiencing negative impressions, causing further distress to the grieving family (Butler, Hall, Willetts, & Copnell, 2015). A simulated experience can provide a valuable opportunity to aid in the preparation for the student transitioning into the role of professional nurse.

“Students frequently articulate anxiety about their ability to transfer classroom learning into clinical practice” (Sinclair & Ferguson, 2009,

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p. 1). Students reported an increase in self-confidence in their nursing practice after participating in simulation experiences (Sinclair & Ferguson, 2009; Wagner, Bear, & Sander, 2009). Bambini, Washburn, and Perkins (2009) suggest students have an increase in confidence following patient simulation. The students also demonstrated an increase in communication skills and clinical judgment. The three C's Themes of Learning During Clinical Simulation (communication, clinical skill confidence, and clinical judgment) highlighted in Bambini et al.'s (2009) study were identified outcome themes by the participants. The identified themes are significant components of nursing education and professional nursing practice.

End-of-life care causes a great deal of anxiety for nursing students. A study by Smith-Stoner (2009) explored the use of simulation to educate students about end-of-life care. Students cared for a simulated patient during the last 10 min of life. The student was able to assess and implement care while observing the patient's response. This design allowed students a firsthand opportunity to experience a simulated end of a life situation before caring for a dying patient in clinical practice. Simulation provides an opportunity for students to process their concerns, emotions and fears, providing a valuable learning experience.

The inclusion of spiritual care education and understanding how to respond to the spiritual needs of an individual during palliative and end-of-life care, should also be infused into the undergraduate nursing curriculum. Nurses, as well as other healthcare providers, are often asked to provide spiritual care at the end-of-life. At a time when connection to one's spiritual self is needed, nurses may not have the skill set or knowledge to offer opportunities to support the child and family during this time of need (Daaleman, Williams, Rawlings, & Hanson, 2008). Having the opportunity to be present, seeing through the eyes of the child and family, and creating a holistic plan that includes spiritual care is within the role of the nurse. Yet the inclusion of spirituality may be unfamiliar for some. By providing the means to simulate spirituality, students can enhance the care they render while aiding a child and their family in coping with death. Nurses spend more time with patients at the end of life than any other health professional (Fabro, Schaffer, & Scharton, 2014). Therefore, it seems fitting that nurses include this essential element as part of palliative and end-of-life care practices.

End-of-life care is not routinely associated with high technology; however, simulations have the potential to renovate palliative care nursing education (Moreland, Myers, & Lemieux, 2012). When standardized patients play the role of the parents, the student nurse is able to react and respond to the distress that is often present when a child dies. Parental grief when simulated by the faculty playing the role of the parent, provides psychological fidelity and adds to the perception of realism for the student (INACSL Standards Committee, 2016). This format also allows participants the opportunity to pause in the event a student is significantly overcome with emotion, or for the facilitator to rerun the scenario if the student responses are deemed unfavorable without inflicting any harm to the child or family.

Design and Methods

A pediatric end-of-life simulation experience was developed in 2016 after course faculty identified the need for a creative learning strategy to connect end-of-life didactic content to clinical practice. The clinical scenario was developed by the course faculty in collaboration with experienced pediatric health care community providers who cared for children and their families during the end-of-life. The curriculum was specifically designed for students in their junior or senior year of a first professional degree-nursing program who were enrolled in the pediatric nursing course. Nursing students were assigned to participate in the simulated experience in the latter half of the semester, after obtaining a baseline knowledge of child health and wellness, developmental stages, and physiological conditions. The simulation focused on three distinct areas: symptom management, communication and family-centered care. Groups of up to four students were assigned to a

simulation experience in lieu of a traditional clinical experience each week. The end-of-life scenario, utilized an unfolding case study format, provided both active and passive roles for all student learners.

Pre-simulation Preparation

Prior to the simulation experience, the students completed pre-simulation assignments which provided them with foundational learning. Preparatory readings topics included Do Not Resuscitate (DNR) and Allow Natural Death (AND), developmental understanding of death, symptom management, palliative and end-of-life care. The readings provided knowledge to assist students in responding to several short answer questions as they prepared for the simulation experience. The International Nursing Association for Clinical Simulation and Learning (INACSL) Standards of Best Practice: SimulationSM endorse pre-simulation preparation to aid in achievement of pre-identified simulation goals. (INACSL Standards Committee, 2016). To further ensure attainment of the simulated experience goals, the simulation faculty facilitated a robust discussion that incorporated the readings and reviewed responses to the short answer questions including questions about DNR and AND status, the importance of effective communication, therapeutic communication techniques, and spirituality. The faculty also shared professional vignettes and provided mock scenarios to facilitate higher order thinking to the discussion. The discussion phase of preparation preceded the simulated experience. Student roles and responsibilities were identified and assigned prior to the initiation of the simulated case execution.

Simulated Experience

The case begins with "report" on an unresponsive young child experiencing a sudden hypoxic-ischemic brain injury. A high fidelity junior manikin is utilized and a faculty member or student portray the role of the parent. The first phase of the unfolding case study begins with the patient breathing spontaneously with intermittent episodes of hypotension and hypoxemia. The child's mother asks, "What is going on with my baby?" "He has all these tubes, why is he not waking up?" While completing a nursing assessment, the student nurses are exposed to physical findings consistent with hypoxia and impaired gas exchange. Their intervention will determine the patient outcome. Students must utilize sound clinical judgment and relevant nursing actions in the provision of care as the child begins decompensating. The student nurse must provide clear communication to the distraught parent while providing nursing care to the child.

The simulation scenario progresses to include a family meeting with the goal to update the family on the child's condition which includes a grim prognosis. The discussion includes helping the family to explore their thoughts about resuscitation measures and supporting the family in making end-of-life decisions. Challenging questions from the distraught parent are presented to the student serving in the role of the nurse. The student responds, in most cases drawing from therapeutic communication techniques previously learned, to the parent. When the student exhibits difficulty formulating a response, or is unable to respond, therapeutic responses, including suggested phrases and the use of silence and presence, are provided to the student for guided learning. The health care provider uses a scripted role and responses within the experience, providing the opportunity for the nurse to engage in dialogue with the medical team and family to address identified concerns. In this phase of the simulation, the health care team and family engage in discussion about a plan of care for the child, providing a rich opportunity for collaboration and team discussion. The family's needs are expressed and the health care team responds.

As the simulated learning experience continues to unfold, the patient requires nursing interventions, including pain and symptom management. A discussion between the nurse and parent ensues and focuses on comfort measures, both pharmacologic and non-

pharmacologic, providing important information for the parent on pain relief during the final stages of life. Some students are conflicted with the concept of double effect and express concern that the administration of a narcotic may contribute to the patient's demise, which provides a valuable opportunity for a rich discussion post simulation. The simulation is ended after approximately 20 min to allow participants time for private reflection before discussion. At the end of the scenario, the family may or may not have communicated their preference to resuscitation measures for their child as the phase length varies depending upon the amount of time spent at each specific phase of the simulation.

Debriefing

Debriefing is used to reflect and reexamine topics discussed in presimulation. This phase of the simulated experience is initiated by quiet reflection. A dialogue among participants is facilitated by the faculty member and includes strengths of the experience, reflective thinking and observations. Several leading questions are posed to the student participants to guide their reflection on the care and needs of the child and family during the end-of-life. The practice of self-care is explored and students are asked to identify and consider methods of self-care. Routinely the students are able to identify the need for emotional, cognitive, and spiritual self-care.

Results

A total of 216 students participated in the pediatric end-of-life simulation experience over three semesters. The simulation–nursing faculty reported that students were engaged in the learning experience. All students “passed” the simulated experience, demonstrating psychomotor skill and knowledge competency based on predetermined evaluation criteria. Post-simulation, students participated in a debriefing session to review psychomotor skills and concepts related to the scenario. In addition, the students completed a four-question post simulation survey that included reflective components. All questions were open-ended allowing for free expression of thoughts and emotions. Of the 149 students completing the written post simulation survey, 57% disclosed prior experience caring for an individual at the end-of-life while only 0.05% ($N = 3$) reported exposure to a dying child and their family.

Several themes emerged from the post-simulation reflection completed by the students:

What to Say?

The majority of students (61%) expressed uncomfortable communication with the child and their family during the end-of-life scenario with the majority (58%) expressing concern about effective/appropriate communication. Students stated they were afraid to “say the wrong thing”. Many expressed uncertainties when “responding to the parent's questions and concerns”, and others conveyed not knowing “what to say”. Thirty seven percent of the students felt the scenario helped them develop communication techniques and strategies however 42% identified that communication during difficult times is a skill they would like to further develop.

Managing Symptoms at the End-of-life

Comfort is a nursing priority when caring for a patient at the end-of-life. Students (25%) expressed concern about providing care that conveyed comfort and cultural competence. Some equated comfort with coping. Others expressed the desire to include the family in any decision making related to comfort. Although students provided pain management during the scenario with pharmacological and non-pharmacological measures, the specific interventions utilized were not mentioned in the reflections. Rather, students reported that the opportunity to “care” for a patient and manage their symptoms was valuable.

Emotional Care

Students identified the emotions, particularly sadness and grief, that are experienced during end-of-life care. Providing emotional comfort and family support was a skill 26% identified learning during the structured simulation experience. Some commented on the importance of allowing the family an opportunity to openly express their feelings. Emotions were displayed during the scenario on the part of the student and the facilitator in the parent role. A few of the student's reflections captured the emotional impact on the student, exploring their role as a nurse and emotional caregiver. The nursing students were surprised to learn that one of the simulation faculty had lost a child of her own. The students felt having the opportunity to ask someone with direct knowledge specific questions regarding grief was very beneficial. Students identified the challenges that exist when caring for the child and their family during an emotional time, including the decisions that are made, communication, emotions and comfort. Self-care was also discussed during the debriefing sessions. Only three students identified spirituality and end of life care in their reflective responses, however, spirituality was discussed and explored during debriefing.

Practice Implications

Based on the themes, the structured simulated teaching strategy provided knowledge, skill and awareness about the role of the nurse when providing care at the end-of-life. The majority of the students participating in this simulated learning experience divulged end-of-life naiveté. While many students had cared for an adult patient at the end of their life in clinical, their communication with the patient and their family was limited. Students expressed that the structured simulated situations that force uncomfortable conversations can be beneficial to learning. Often times, in clinical practice, nurses' first encounter with difficult and emotional exchanges manifest without adequate time or opportunity to role-play. Simulating this end-of-life experiences provided students with time to reflect on their feelings and experiences and evaluate the effectiveness of their dialogue. Debriefing allowed the students an opportunity to reflect on emotions, word choice, and overall nursing presence. It also allowed the student a time to confront their emotions and supportiveness. Students felt that starting the conversation was the most difficult part. Affording students an opportunity to simulate difficult conversations with the aid of scripts facilitated the initiation of open-ended dialogue using language that eased their fears.

It is clear that students understood the immense challenges faced by the nurse delivering end-of-life care. Although students understood the child was the priority, they discovered the importance of being, “realistic” when supporting the patient and their family. They also recognized the need for honesty and genuineness to effectively deliver family-centered empathic care during an emotional time. In practice, crucial conversations are often times conducted using a multidisciplinary approach. Although this scenario did allow students to integrate the role of the health care provider, future end-of-life simulations could incorporate additional roles such as social work and clergy to heighten the realism of the experience.

Students did not mention spirituality in their reflective responses, however it was discussed during the debriefing. This area will need further emphasis to ensure students understand how spiritual needs are assessed and care can be provided during palliative and end-of-life care. Spiritual care assessment and interventions can be included in the pre-simulation preparation to promote increased knowledge for application in the structured simulation experience.

Conclusions

Nurses spend the most time at a bedside with a child and their family. It is imperative that the nurse has the skills to care for the psychological, physical and spiritual needs of the child and family. Having the

opportunity to “care” for a patient who has unique and sensitive needs with guidance, support and feedback was beneficial to the student.

Effective and sensitive communication is essential in nursing practice. Students identified a need for future skill development when caring for patients and their families during times of crisis. Not knowing what to say or how to say it was a concern expressed by the students. The structured simulated experience raised awareness and sensitivity to the communication needs of this identified population and for their own need for growth in this area.

Symptom management is included in most nursing courses. Students were able to apply their previously learned knowledge to the newly introduced concepts and apply them in the simulated setting. Students, debriefing following simulation did not focus on symptom management and the role of the nurse as heavily as communication during the end of life.

Spiritual considerations were incorporated in the simulation experience. Questioning “why” (a person is ill or dying) is often posed to the nurse. Students often struggled in response to this question. The structured simulation experience provided the student with some basic communication responses to consider. This experience provided the student with the opportunity to provide care and address the needs of the child and family.

Credit authorship contribution statement

Michelle A. Cole: Conceptualization, Formal Analysis, Resources, Writing-original, Review and editing, Visualization. **Kimberly Foito:** Methodology, Validation, Resources, Writing-Review and Editing.

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