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EXPERIENCES OF PAEDIATRIC END-OF-LIFE SIMULATION IN UNDERGRADUATE CHILDREN'S NURSING STUDENTS: A QUALITATIVE STUDY

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ABSTRACT

Background: End-of-life-care (EOLC) simulation is a new concept preparing student nurses for clinical practice. The aim of this study was to explore the experiences of undergraduate children's nursing students participating in simulation of the imminent death of a child.

Methods: A sample of 39 third-year children's nursing students participated in an open-ended questionnaire and five students participated in a focus group. Data was analysed using thematic analysis.

Results: Four themes were identified. 1) 'Learning how to communicate in an end-of-life situation' including challenges faced by participants in communicating with parents. 2) 'Emotional impact of end-of-life simulation' demonstrating significant emotional impacts on participants. 3) 'Value of simulation for teaching end-of-life care' with all participants reporting the simulation training as useful and providing a positive experience for learning despite the emotive nature. 4) 'Preparation for practice' reporting that simulation has prepared students to deliver EOLC in practice.

Conclusion: The findings support the use of simulation as a method of teaching EOLC. There is a need to ensure the emotional safety of student nurses engaging in EOLC simulation.

HIGHLIGHTS

- Communicating with parents during end of life care for children generates anxiety for student nurses

- Simulation provides safe space to explore communication with family during end of life care

- The use of high-fidelity simulation offers an opportunity to witness some of the deteriorating symptoms in the child at end-of-life

KEY POINTS

- Qualitative study exploring experiences of student nurses in paediatric end of life simulation.

- End of life simulation provides a valid alternative to didactic teaching to prepare children's nursing students for the future.

- The emotional safety of student nurses engaging in end of life simulation needs to be supported in a safe learning environment.

KEY WORDS

Simulation; Children; Nursing; Students; End of life care; Education; Pediatric.

INTRODUCTION

Undergraduate nursing students need to be adequately prepared to deliver specialist care to children and young people requiring end-of-life-care (EOLC) (Gillan et al, 2013; Dame and Hoebeke, 2016; Shaw and Abbot, 2017). During the terminal phase of illness, children suffer due to poor recognition of distressing symptoms and delayed management (Lidstone et al, 2011). Although reasons for this are unclear, there is evidence that points towards fear, anxiety and sadness among nurses caring for dying children, which are attributed to feelings of being unprepared to deliver specialist EOLC (Gillan et al, 2013; Sherlin and Quinn, 2016).

Bassah et al (2014) reported that the delivery of theoretical content alone as not being adequate when delivering EOLC education, exposure to practice being an essential component of learning. With limited clinical placement opportunities for exposure to EOLC in practice, the use of high-fidelity simulation may then provide a valued alternative. Simulation in EOLC education is increasing in popularity compared to the more traditional, didactic teaching, with several studies exploring its use in undergraduate nurse education (Dame and Hoebeke, 2012; Kirkpatrick et al, 2019; Gillan et al, 2016; Cole and Foito, 2019). Simulation to teach EOLC education to children's nursing students in our university was formally introduced into the curriculum in 2018. Therefore, we wanted to explore the experiences of undergraduate children's nursing students participating in EOLC simulation to improve students practice in EOLC.

THEORETICAL FRAMEWORK

The use of EOLC simulation began to emerge in the literature in the last decade. In 2009, in America, several studies explored the experiences of nursing students and

faculty engaging with EOLC simulation (Leighton and Dubas, 2009; Smith-Stoner, 2009; Sperlazza and Cangelosi, 2009). Fluharty et al (2012) explored the use of EOLC simulation teaching on students' experiences. Their findings demonstrated an increase in knowledge, self-confidence, communication skills and satisfaction in students following engagement with EOLC simulation with a significant increase in knowledge in the post-test data.

Several studies have since explored the use of EOLC simulation (Kopp and Hanson, 2012; Gillan et al, 2016; Shaw and Abbot, 2017 and Sherlin and Quinn, 2016). These studies evaluated an EOLC simulation activity, all presenting an adult patient at end-of-life. The studies presented similar themes with a focus on the importance of debrief. The emotional impact upon nursing students was also discussed, with Sherlin and Quinn (2016) focussing almost entirely on the emotional response of students to end-of-life simulation, making several recommendations regarding the importance of debrief, student preparation, and peer support. These echoed earlier recommendations made by Hamilton (2010) who identified the importance of debriefing but also introduced the concept of 'de-griefing', suggesting that faculty must allow students to openly express and reflect upon their emotions relating to the distress of loss.

More recently, Weil et al (2018) studied the use of sequential simulation to teach EOLC to multi-professional staff within a hospital environment. They demonstrated a significant increase in self-reported confidence from all professionals after engagement in the simulation activity. Findings from their study were supported by Cole and Foito's (2019), concluding that EOLC simulation provided a valuable opportunity for student nurses to explore the role of registered nurses in delivering EOLC as well as enhancing their own skills, knowledge, and confidence. The authors

further suggested that, whilst most students had some clinical experience in caring for a dying adult, many of the students lacked the confidence to communicate with patients at end-of-life.

Whilst the literature supports the use of EOLC simulation in nursing education, the focus is almost entirely on adult student nurses with a gap in the experiences of children's nursing students. Therefore, the aim of this study is to explore the experiences of undergraduate children's nursing students participating in a simulation training of the imminent death of a paediatric patient.

MATERIAL AND METHODS

This study adopted a pragmatic qualitative design. Given the setting of the study, we used a survey with open-ended questions and a focus group. Following theoretical content earlier in the programme, the EOLC simulation training was organised across three days with a cohort of 55 children's nursing students and took place in a simulation laboratory. The simulation laboratory was designed to depict a children's ward of our university hospital. The guideline 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups' was used to report our study (Tong et al, 2007)

Simulation

An end-of-life simulated scenario was developed utilising a high-fidelity simulator to portray a 7-year-old dying child with an acquired brain injury admitted to the children's ward with increasing, uncontrolled seizures and pneumonia. The child's mother was present throughout and was portrayed by a member of the academic staff. Prior to the simulation, all students had engaged with the simulator regularly throughout their three-year programme and were familiar with the functions of the manikin as well as

being well practiced in simulation. The students had access to resources on their digital learning platform for the simulation module. In relation to EOLC simulation session, resources were available for the students that explore palliative and end of life care in paediatrics. These resources were suggested reading rather than mandatory.

During the simulation sessions there were three academic faculty members present (with the exception of one day where there were only two faculty members present due to staff sickness). One faculty member played the part of the parent, one led the simulation and one was available for student support should this be required due to the emotional nature of the simulation. The faculty members did not receive formal training however, all attended a pre-brief to discuss how the simulation would progress and to ensure a plan was in place should any student become distressed. All faculty members also attended a debrief immediately after the simulation, this is standard practice for all simulation activities within our University.

Preparation of the EOLC simulation sessions initially involved writing the scenario and information regarding progression of the simulation and gathering resources (paediatric palliative care formulary, drug chart, simulated drugs, personal effects of the child to enhance fidelity). This initial preparation was around two hours. The faculty pre-brief was held over a period of 30 minutes prior to each simulation, this is standard practice for all simulation sessions as part of this module.

Students were split into small groups of seven students. Prior to the simulation sessions, a pre-briefing was held where students were informed that the manikin would die during the simulation. This gave the students time to consider their responses and to prepare for the emotional impact this may have.

Students within each team were allocated roles with three to four students playing the role of the nursing team and three to four students observing the simulation to provide feedback during the debrief. The students playing the role of the nursing team were given two minutes to prepare during which they allocated themselves team roles and were able to familiarise themselves with the equipment available and the child's medication chart.

The simulation scenario lasted ten minutes with the child showing signs of imminent death through deteriorating conscious level, desaturation, reduced respiratory effort and decreasing heart rate until asystole at which point the students comfort the mother and confirm death.

Participants allocated to observe the simulation were given specific tasks as recommended by Smith-Stoner (2009) to support engagement in learning. The observers were to observe and provide feedback on communication, team working and family centred care; this facilitated discussion during the debrief. After each simulation session and subsequent debrief, the teams swapped so each team had the opportunity to actively participate in the simulation and observation.

Following the simulation scenario, students then participated in a twenty minute debrief following the 'debriefing diamond' model (Jaye et al, 2015) which encourages students to consider the non-technical aspects of a simulation.

Participants

Participants were recruited from a convenience sample of year three nursing students (n=39) enrolled onto a three-year, undergraduate child health nursing Bachelor of Science degree programme. Students were engaged in the simulation as part of their programme; exclusions were those students who were unwilling to participate in the study.

Data Collection

Data were collected from a post simulation evaluation survey with four open-ended questions developed by Gillan et al (2013) (Box 1), and a focus group held after the simulation. The post simulation evaluation survey was provided to the students in a paper format and was completed immediately after the debriefing at the end of the simulation session while the researcher – who was also a faculty – was present. The focus group was held one week after the final simulation day.

The focus group discussion was held in a quiet room on university campus and conversations were recorded, transcribed, and uploaded onto a password protected computer. The researcher (NF) guided the initial discussion during the focus group by asking participants an opening question: '*Please reflect upon your experiences of the EOLC simulation'*. The focus group was guided to discuss the structure, process, and outcomes of the EOLC simulation experiences by prompt questions.

Data Analysis

Data were typed into a word document and analysed using thematic analysis following Braun and Clarke's (2006) 6-step framework. Step 1 was familiarising with the data: the responses of the surveys and the transcripts of the focus group was reviewed several times. Step 2, generating initial codes, the meaningful text fragments were grouped to form emerging codes. Step 3, searching for themes, was performed by collating codes into sub-themes. If uncertainty appeared in this process, the quotations linked to the codes were reviewed back to better understand the underlying meaning of the codes and the sub-themes. Step 4, reviewing themes, was performed by combining sub-themes to themes. Step 5, defining and naming themes, was the ongoing analysis of reviewing the codes and generated (sub)themes. Refinement of the themes was considered to improve the clarity and relevance of the themes. This

process was performed with a second researcher (JML). Any disagreement of the codes, sub-themes and themes was resolved by discussion with a third researcher (JK). Step 6, producing the report, is the result of this paper.

The narratives used in the findings are anonymised by codes using, for example, FP1 is focus group participant 1 and SP2 is survey participant 2.

Rigour and Trustworthiness

During the completion of the survey and the focus group only the researcher, who is also an academic faculty, was present and may have affected responses of participants (Anderson, 2010). It can be a challenge to ensure that any pre-determined experiences do not impact upon the interpretation and analysis of findings (Harvey and Land, 2017). To ensure transparency, limiting the impact of any preconceived thoughts or experiences by the researchers, the raw data and summary of themes and sub-themes were reviewed and discussed by a third researcher (JK) (Moule et al, 2017; Harvey and Land, 2017).

Ethical Considerations

Ethical approval was obtained from the Faculty Research Ethics and Integrity student sub-Committee (FREIsC-2019-02). Written information was provided to students prior to the simulation day and was explained verbally at the beginning of each simulation day. Written consent was obtained prior to the start of the simulation day. Participants were informed that the data would be anonymised. Participation in the study was entirely voluntary and their participation would not affect the overall grade for the module. Should students require additional support during or after the study, pastoral support would be available from the academic team or their personal tutor.

RESULTS

A total of 39 participants completed the survey and five of these participants agreed to participate in the focus group. All participants were female and 33 (84.6%) were under 30 years of age, with a third (n=13; 33.3%) aged 20 or 21 years. The youngest participant was 20 years of age and the oldest 38.

The findings resulted in four themes derived from 16 sub-themes:1) Learning how to communicate in an end-of-life situation; 2) Emotional impact of end-of-life simulation; 3) Value of simulation for teaching end-of-life care; 4) Preparation for practice (Table 1).

Learning how to communicate in an end-of-life situation

Most participants identified the importance of communication in an end-of-life situation. Although most participants identified communication with family in their responses, there were also several responses relating to communication skills more generally. Several participants also identified the importance of silence. Participants of the focus group reported communication with family as a skill learned during the simulation with a particular focus on delivering bad news to parents. There was discussion during the focus group around communication and an associated feeling of helplessness when participants did not know what to say to parents: *I found it hard to communicate with mum because I didn't want to ask questions like 'did he like to go to school?' I just didn't know what to say so we just put his favourite Peppa Pig song on and just sat there and I just thought… I actually do not know what to say* (FP29).

The focus around communication was predominantly on how to communicate with parents. However, one student reported some difficulty in knowing whether to direct her communication to the dying child or to the parent saying: *It's hard to find a balance: do I talk more to the child or to the parent? I found that hard* (FP18).

Terminology used when communicating with parents was also identified as a challenge, specifically the reluctance to use the word 'died': *I observed the first group and they didn't say that the boy had died, they said 'passed away' or something… Then I was the one talking to mum later on and I said to myself that I will try and say to the mum that he had died and that was interesting, it was really quite hard to say it and felt really blunt* (FP18).

Emotional Impact of end-of-life Simulation

Many participants reported an emotional impact to the simulation with some identifying a physical response such as crying: *I got quite emotional and I know that members of my group were quite emotional, one of them cried throughout* (FP29).

A small number of participants reported negative feelings towards the emotional impact with one participant identifying the simulation as a '*very emotional and scary situation to be in'* (SP18). In addition to the emotional impact of the simulation, many participants identified the emotional impact of EOLC in practice. Responses demonstrated a degree of reflection among participants and were mostly related to the participants' ability to manage their own emotions in end-of-life situations, for example *High emotions but good to think about how this impacts your own practice* (SP10).

Value of Simulation for Teaching End-of-Life Care

All participants reported value to the simulation in relation to several different factors from an increase in confidence to acquisition of skills. There was a focus among participants on the use of oxygen and monitoring for patients at end-of-life: *The last group saw the sats (oxygen saturations) went down so they put oxygen on and we discussed why, because the oxygen didn't make a difference, the sats still went down. It was quite interesting because we automatically go to put oxygen on but if the monitor wasn't on, we wouldn't know that the sats dropped* (FP29). This dilemma was

discussed in depth during the focus group and was attributed to a feeling of helplessness.

The opportunity to consider ethical issues in a safe and supportive environment is a clear benefit to simulation with many participants reporting an increase in confidence following the simulation. Most of the participants also reported the value of being able to learn new skills and practice these in a supportive environment without the fear of making mistakes with one student saying: *It definitely gives you an idea of what you'd do towards the end of a child's life… because none of us had a clue what you're supposed to do, what you're supposed to say* (FP38).

Realism and fidelity are recognised challenges in simulation and was identified by participants in both the surveys and focus group. Most participants reported the simulation to be realistic. However, some participants mentioned that the substitute of a real patient for a high-fidelity manikin was a significant barrier to learning: *It is very distressing and it is difficult to imagine as 'Simon' is a doll and it is hard to imagine the lecturer as a real mother* (FP24). Nevertheless, all participants reported a value in EOLC education in general with most suggesting a need for theoretical content alongside simulation.

Preparation for Practice

Many participants reported the value of the simulation, alongside theoretical content, in preparing them for future practice: *Education component is important in lectures because it gives you baseline information of what to do but the scenario definitely prepares you* (FP31).

Participants also identified ability to link knowledge learned in theory to their future practice with one participant explicitly listing this as a skill learned during the simulation: *Learning how to adapt my knowledge into practice* (SP9). Whilst some

participants were explicit in identifying specific skills learnt, others identified the value in being able to practice such a scenario before experiencing this in clinical practice.

DISCUSSION

The aim of this study was to explore the experiences of undergraduate children's nursing students participating in a simulation of the imminent death of a paediatric patient. The role of parents is paramount in paediatric EOLC and nurses are at the forefront in communicating with parents at the bedside. In this perspective, paediatric EOLC simulation should not only focus on the death of a child but must include parents in these situations. The importance of having a family member in the simulation can create fidelity since this would be occurring in real life. Although there is limited evidence related to including the presence of family members in EOLC simulation, experiences from a centre in the USA suggest to include actors in simulation sessions to prepare the competency, confident, and empathy in healthcare professionals (Pascucci et al, 2014).

Communicating with parents during EOLC for children appeared to generate anxiety for many participants. This is echoed in the literature with the impact of a family member present during end-of-life simulation identified as a significant challenge to students (Leighton and Dubas, 2009; Smith-Stoner, 2009; Gillan et al, 2013; Dame and Hoebeke, 2016; Sarabia-Cobo et al, 2016; Kirkpatrick et al, 2019). Most of these studies recruited academics or patients to play the role of the relative with the exception of Gillan et al (2013) who allocated the role of a relative to one of the participating students. In our study, the mother was played by an academic faculty member. There is limited evidence in the literature relating to the benefits of including

the presence of family members in end-of-life simulation. However, those studies having a family member present identified a benefit to the learning of the students.

The emotional safety of participants during the EOLC simulation was considered an integral part of preparation for the academics. It is documented that simulation of any kind often results in increased anxiety in undergraduate students (Yockey and Henry, 2019). Whilst the cause of this anxiety is often multi-faceted, it could be assumed that the emotive nature of EOLC may contribute significantly to such anxiety. This was reflected in the responses of participants in our simulation sessions with one participant stating she was *'going to cry anyway'* when informed of the nature of the simulation. It is acknowledged that there is a significant emotional impact of end-of-life simulation on undergraduate nursing students (Sperlazza and Cangelosi, 2009; Sherlin and Quinn, 2016). A responsibility is placed upon faculty to ensure emotional safety of students throughout the simulation (Gillan et al, 2013). The availability of experienced academics to immediately identify and support participants in distress during this study meant that the simulation continued with little disruption for the remaining participants.

The use of simulation to teach EOLC has increased in undergraduate nursing education over the past decade. Most participants in our study identified the opportunity to practice EOLC in a safe and supportive environment without the fear of making mistakes. This is supported by Sherlin and Quinn (2016) suggesting simulation provides a valuable opportunity for students to explore their own feelings about EOLC and how those feelings may affect patient care. Findings of our study demonstrated this by allowing students to experience the emotional impact of EOLC in a simulated environment to prepare for clinical practice.

The use of high-fidelity simulation offers an opportunity to witness some of the deteriorating symptoms in the child at end-of-life. However, there are some recognised barriers to fidelity in this type of simulation session. The ability to portray physical symptoms or a more complex verbal response to questions is limited. Many participants in our study suggested the simulation felt real for them. However, some participants suggested they found it difficult to imagine the manikin as a real child. This challenge to create realism in simulation was identified by Smith-Stoner (2009) and Sherlin and Quinn (2016). Smith-Stoner (2009) suggested a challenge in portraying physical symptoms in a manikin, particularly respiratory symptoms such as Cheyne stoke. A decade later, advances in simulation technology has seen development in the ability to portray such symptoms in high-fidelity manikins. However, Sherlin and Quinn (2016) also identified challenges to creating realism in portraying end-of-life symptoms and offer suggestions to address this, such as the use of make-up.

One of the aims of undergraduate nursing education is to prepare students to become autonomous nurses in practice. Participants in our study identified the value of simulation in preparing them for experiencing end-of-life in practice. This was also addressed by Gillan et al (2013) reporting the value of a 'hands on experience' within a protected environment. The concept of linking theory to practice has been described by Kopp and Hanson (2012) suggesting that simulation can close the gap between theory and practice as well as promoting critical thinking in nursing students.

Limitations

The nature of using a qualitative design might have limited the deeper understanding of nursing students as we only used four open-ended questions within the survey and performed only one focus group. The sample in our study was relatively modest, and the participants were part of the same cohort of students in one university, limiting the

ability to generalise its findings. A study using phenomenology as a study method exploring nursing students' experiences of EOLC simulation with in-depth or semi-structured interviews might reveal new findings. Consequently, the findings of such a study and our findings can contribute to the development of an explorative survey for a quantitative study with a larger cohort of nursing students contributing to the evidence based in improving EOLC simulation teaching and learning of nursing students.

CONCLUSIONS

The findings of our study support the use of EOLC simulation in undergraduate children's nursing education. The emotional safety of student nurses engaging in EOLC simulation needs to be supported in a safe learning environment. It is the responsibility of undergraduate nursing schools to ensure they prepare children's nursing students appropriately related to EOLC. Whilst the provision of EOLC education within undergraduate nursing programmes is increasing, this is often by means of didactic teaching of theoretical content. The exposure of learning EOLC in clinical practice is limited, our findings support the use of EOLC simulation and may provide a valid alternative to prepare children's nursing students for the future. The relationships between the provision of EOLC simulation and clinical performance and patient outcomes is yet undetermined with a need for further research to explore this.

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<u>Box 1. Post simulation evaluation survey</u>

Post Simulation Survey of Experiences

Q1. Please list any skills you have learned during this simulation

Q2. What were the benefits of the simulation?

Q3. Were there any negative aspects of the simulation? If so, what?

Q4. Could you please make an overarching statement to describe your experiences with this simulation?

Adapted and with permission from Gillan, Parmenter, Van der Riet and Jeong (2013)

Table 1. Summary of Themes, Sub-themes and Quotations

Themes	Sub-themes	Quotations
1. Learning how to communicate in an end of life situation	1. Communication skills	Improved communication (SP35)
		Knowing when to say nothing (SP13)
	2. Communication with child and family	How to communicate with parents during an emotional situation (SP19)
		Knowing when to speak to mum (SP12)
	3. Terminology	Learning to use the word 'died' (SP16)
		Improved communication in regard to terminology (SP22)
	4. Difficult conversations	How to break bad news (SP26)
		Compassion and difficult conversations (SP37)
	5. Team working	Importance of supporting your team (SP10)
		Importance of collaborative working (SP12)
2. Emotional impact of end of life simulation	1. Emotional impact of EOLC simulation	Very emotional scenario (SP23)
		I got quite emotional and I know that members of my group were quite emotional (FP29)
	2. Emotional impact of EOLC in practice	Allows you to think about the emotions that may be felt during that situation (SP34)
		High emotions but good to think about how this impacts your own practice (SP10)
3. Value of simulation for teaching end of life care	1. Ethical considerations	Monitoring and oxygen, making decisions when to take it away/give it (SP38)
		Use of Morphine for dyspnoea, use of monitoring at end of life (SP36)
	2. Impact on confidence	Nerve wracking to begin with but actually provides you with a really good confidence boost (SP30)
		It has made me more confident in palliative care (SP6)
	3. Supportive environment	Being able to carry it out in a supportive environment made it easier to do (SP7)
		Very worthwhile and pleasant to learn in a supportive environment (SP14)
	4. Skill acquisition	What the nurse's role is in end of life situations (SP34)
		Gives you an idea of what you'd do towards the end of a child's life (FP38)
	5. Realism of simulation	Quite realistic so have given me an insight and somewhat prepared me for future cases (SP39)
		As realistic as it possibly can be without it being a real patient (FP29)
	6. Value of EOLC education	Huge benefits! Understanding the end of life situation, nurse's role and knowing it's ok not to intervene (SP17)
		For my own emotional well-being and knowing what to do or say (SP29)
	7. Simulation as a teaching method	More beneficial than just lectures (SP31)
		Allowed us to practice as well as get a feel for what it would be like (SP39)
4. Preparation for practice	1. Linking theory to practice	Being able to reflect what I have done in previous practice (SP25)
		Learning how to adapt my knowledge into practice (SP9)
	2. Preparation for end of life situation	Really useful to have and has definitely prepared me (SP31)
		Preparing for a real scenario (SP7)

EOLC=End Of Life Care