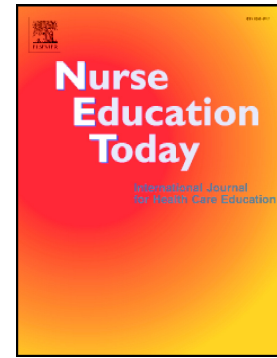


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Experiences of nursing students providing end of life care for children and young people: A focus group study

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Title Page: Experiences of Nursing Students Providing End of Life Care for Children and Young People: A Focus Group Study.

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Experiences of Nursing Students Providing End of Life Care for Children and Young People: A Focus Group Study.

Introduction

The number of child deaths in the UK varies year on year but has been relatively stable for the last decade (Royal College of Paediatrics and Child Health (RCPCH) 2014; 2017; Office of National Statistics (ONS) 2021) with infants under 1 accounting for more than 50% of the deaths each year (ONS, 2021). The Department of Health (2013), identify the UK as having one of the highest child mortality rates within Western Europe, although this is dated the infant mortality and child mortality rates have not seen significant improvement over the last decade (Marmot et al, 2020; RCPCH, 2020, ONS, 2021). Although Children and Young People (CYP) die in a range of settings and for a range of reasons, caring for CYP during the end of their life is recognised internationally as an emotional, stressful and at times, traumatic, experience (Plant and Cyr, 2011; Nurse and Price, 2016; Chew et al, 2020; Dalach et al, 2020). While there is an established body of literature on the experiences of nurses post initial education and certification (qualified nurses) caring for CYP at the end of life (Shorey and Chua, 2022), there is far less known about the experiences of student nurses within children and young people's nursing (Carson, 2010; Cole and Foito, 2019).

Background

The experience of caring for a family at the end of a child or young person's life is unique for every patient and can be both a challenge and a privilege (Bloomer et al, 2015; Mullen et al, 2015). Thankfully, the death of CYP is still rare and a qualified children's nurse may never care for a child or young person during the end of their life. However, there are areas of practice where experiencing death is more likely. Student nurses, who study children and young people's nursing (referred to throughout as 'student nurses') in the Northeast of England, undertake placements that may include: intensive care, critical care, emergency departments, specialised children's wards and hospice care, during which, they may care for CYP at the end of their life.

Qualified nurses have different levels of exposure and experience when supporting CYP and their families during end-of-life care and have reported a lack of knowledge and effective education which can then impact on their own confidence in care provision and support of students (Anderson et al, 2014; Nurse and Price, 2016; Cole and Foito, 2019). This can be made more complex internationally as in some countries, the discussion of death is a taboo subject (Bian et al, 2023).

Literature on the experience of caring for CYP during end-of-life care is limited. Available studies in the main have focussed on specific practice areas such as neonatal intensive care or special care baby units (Kain, 2013; Nurse and Price, 2016; Dalcali et al, 2020); paediatric intensive care units (Stayer and Lockhart, 2016; al Mutair et al, 2019); palliative care specialist nurses (Santos et al, 2020) or in one case nurse participants from a mixture of these settings (Chew et al, 2021). Only one study found addressed the experience in a general hospital (Plant and Cyr, 2011) although the ward areas were not specified. The available articles mainly focussed on qualified healthcare staff, occasionally with student nurses included as part of the MDT rather than specifically focussed on students themselves.

Nurses reported feeling they need further end of life care education (Plante and Cyr, 2011; Chew et al, 2021), as well as a platform for sharing experience and discussing it with others (Chew et al, 2021). Internationally, nurses have raised the importance of spirituality for comfort and support of families (Santos et al, 2020), evidence from the UK suggests that nurses do not always feel confident

in providing spiritually or culturally appropriate care due to lack of knowledge and understanding (O'Brien et al, 2018). Yet evidence relating to student nurses remains limited (Cole and Foito, 2019) despite no or little exposure in practice. This study begins to address the gap in the literature with the aim of understanding the student nurses experience of caring for CYP during end-of-life care and enable educators to develop pre-registration education for practice and also guide placement supervisors/ assessors in the needs of student nurses and how to support the students more fully.

Aims:

- To understand the lived experiences of student nurses who have cared for a patient at, during, or immediately following end-of-life.
- To describe the emotions experienced by student nurses in reference to caring for a child or young person during end-of-life care.
- To explore the student nurses' perceptions of education and support needs around caring for CYP during end-of-life care.

Methodology

This was a co-designed project, with the initial idea being proposed by a student nurse who has since qualified and is now a practicing CYP nurse. As there was a paucity of current literature from the student nurse's perspective and the aims of the project sought to address this, a qualitative project was deemed appropriate (Creswell, 2013; Nurse and Price, 2017). A generic qualitative inquiry methodology aligned to qualitative description allows for a pragmatic approach to a question human experience and impact of social interaction while staying close to the original descriptions of the participants (Patton, 2015, p.154- 160; Bradshaw, Atkinson and Doody, 2017; Kostere and Kostere, 2022) this was the methodology used. The methodology allowed for the collection of rich descriptions from the perspectives of the participants, parts of which are included in the findings.

Ethical approval was granted by details in authorship statement and the study collected data from 2022 when safely able to both collect and support student participant.

Recruitment and Sampling

All undergraduate students on the Nursing Science: Children and Young People's Nursing BSc course were offered the opportunity to be participants. The student nurses that expressed interest and had experience of the phenomena were included in the research. The demographics of the participants were not recorded although their year of practice is represented in Table 1.0.

The programme of study that students were enrolled on involved a 50/50 split of academic based theory and practice placements in healthcare environments. The focus groups were conducted in Spring. As such, the students in year 2 had experienced four placement environments, whilst the students in year 3 had experienced seven placement environments across a range of community and hospital settings. Some participants had only experienced the death of one patient whilst others had witnessed end of life care for numerous children and young people. Student nurses in their second year had received no theory on caring for CYP at the end of life and student nurses in their third year had attended one taught seminar in university with this focus.

Insert table 1 here

Data was collected using small focus groups (4-5 participants per group), while perhaps smaller than average (Freeman, 2006) the group size was kept intentionally small due to the potentially emotive subject matter. However, it was intended that the group setting would encourage discussion, facilitating participants agreements and disagreements with each other and allowing for comment

and explanation between peers (Freeman, 2006; Tausch and Menold, 2016; Gray, 2022). The focus groups lasted between 60 and 90 minutes and was followed by peer debrief as recommended by Nowell et al, (2017) focussed on facilitator technique.

Data Analysis

Initial themes were generated based on the steps set out in Braun and Clarke (2006) but also in context of subsequent thematic analysis writing (Braun and Clarke, 2016; Nowell et al, 2017; Braun et al, 2019). For the first phase of data analysis, all three authors independently familiarised themselves with the data. Authors 1 and 2 conducted the initial focus groups and transcription, with transcription checked against audio recordings by the alternate, so were able to familiarise themselves through these processes and rereading of the transcripts. Author 3 conducted analysis solely through reading of the transcripts. This would allow for triangulation of the data at a later phase.

Repeated reading by individual authors allowed for the creation of initial codes and categories in phase two of data analysis, before authors also independently constructed initial themes in phase three. At this stage, each of the authors came together and data triangulation was undertaken to review themes, define and name themes and then produce the report a per phases four to six of Braun and Clarke's (2006) guide. No disagreements occurred as all researchers had generated codes and themes with similar meanings, so titles were negotiated and agreed. All participants were invited to a follow up meeting post data analysis to discuss findings and discuss their feedback.

Rigor

To verify credibility researchers have undertaken qualitative research training, member checking and peer debriefing (Birt et al, 2016; McMahon and Winch, 2018). Explanations and quotes accompany themes alongside thick descriptions to increase transferability. A reflexive diary was used by the lead researcher to aid in questioning any assumptions or biases.

Findings

Six themes emerged from the data; Emotional practice (1), the heart of the care (2), a lasting impact (3), hierarchy of grief (4), experience, knowledge and understanding (5), and the value of support (6). Table 2.1 demonstrates how these themes were generated.

Insert table 2.0 here

Emotional Practice

The first theme to arise from both focus groups was that of the emotional nature of nursing practice when caring for CYP at the end of life. Participants identified varying reactions, both emotional and physical, from crying to disturbed sleep and anxiety. This was also often linked to an attempt to hide or control their emotions until such a time that it was felt acceptable to react.

"Me and my mentor went into the break room and me and her just sobbed because we didn't want to do it in front of them. We didn't want them to see anything, but then when we came out, we did cry. Because it was just so emotional watching it all." (P8, FG2, line 242)

Participants also described how they expected to cry or feel sad but were often surprised by their lack of emotion too. Within both focus groups, participants gave examples of times when they felt little or nothing.

"I just felt empty like I felt like it sounds really bad, but I just felt like nothing like no emotion at all. I think because I was in shock because it was my first child death." (P1, FG1, line 60).

Both focus groups also identified that the timing or unpredictability of deaths had an impact on the emotional response generated. Participants identified that deaths which happened quickly, or were unexpected, caused a greater emotional response than situations where children or young people were expected to be at end of life.

"It was just a massive shock going from so close to recovering, such happy family, to then we will have to switch the ECMO off and everything." (P8, FG2, line 59)

The Heart of the Care

Within both focus groups, the idea that the CYP and the family were at the heart of end-of-life care arose. This was sometimes identified as being a barrier if families made decisions at odds with the health professionals or student nurses own views.

"It's just hard to kind of, it's the parents decision to keep the airvo on. You can't then tell them what you think." (P9, FG2, line 197)

Caring for the family was often viewed as being the most difficult aspect of end-of-life care. Participants vocalised that witnessing families being delivered bad news was often more emotive than caring for the child or young person themselves.

"So Mum was just on the phone ringing like everyone she knew. Please pray, please pray. And I think it was, being with the family was harder." (P3, FG1, line 66).

A Lasting Impact

Though it was identified that end of life care for CYP is always emotive, for participants who had cared for more than one child or young person at the end of life, they recognised that often some experiences affected them more than others and had a lasting impact. For some participants this was about a child or young person who they had spent more time with or had a stronger relationship with.

"I think it made me quite invested. Now, I can't forget. Like now, I don't forget any of it. And I was inquisitive I did want to know." (P2, FG1, line 229).

In other situations, the experience that had a lasting impact on the student nurse was because of trauma or a particularly difficult situation. This was discussed both in terms of deaths that happened quickly or those where end of life wasn't expected.

"Honestly it's all I heard for 2 weeks straight with that scream in my head, whenever I closed my eyes." (P8, FG2, line 217).

Hierarchy of Grief

The idea that student nurses didn't have a right to grieve arose from both focus groups. In focus group 1 this was demonstrated by students feeling they weren't included in care planning, discussions, or debriefing.

"I feel that we just kind of get, I don't know... like pushed to the side a little bit". (P4, FG1, line 297)

In focus group 2, the idea of a hierarchy or grief was clearer. Participants distinctly vocalised that they felt the grief of the family was the most important.

"I don't want to take away from their loss by me being upset and like me grieving over their child that I don't even know that they've had for years. But obviously, like you say, you get to know their families and you do get close to them, but, I think you do sometimes feel like it's not your place or your position to be upset about it." (P7, FG2, line 441)

Participants also identified that they felt that people who needed support often did not receive this. They gave examples of times when both qualified and unqualified healthcare staff who had spent large amounts of time caring for CYP at end of life weren't included in aftercare or weren't as well supported as other staff. The participants also identified that as students were only on the wards for short periods or part time, they were not expected to be as invested in the care.

"I'm really upset then like maybe they'd be like why, like you were only here two days a week." (P9, FG2, line 390).

Experience, Knowledge and Understanding

Participants in both focus groups identified that they felt they were unprepared to care for CYP at the end of life. This was firstly identified as a sense of being unprepared emotionally for how they would feel when faced with this experience.

"I was really like, what's wrong with me, I was like, all the adrenaline's gone. I was knackered but I felt alright, I didn't, like, I haven't cried about it. I feel kind of OK, but just kind of I guess normalising that actually it's OK not to cry and everyone has different reactions to it." (P3, FG1, line 468).

Secondly, participants in both focus groups identified they were unprepared with the knowledge and understanding they felt they required to deliver end of life care. Participants identified that they didn't know what physical symptoms to expect from the children and young people. They also identified they felt lacking in knowledge for how to speak to the families of CYP at end of life. Additionally, some of the medical language used left them feeling unprepared.

"They were like oh yeah, a kid, got withdrawn and I'm like what does withdrawing mean? When I first started, like what does that mean? What happened to the baby? How was the baby born was the baby unwell, was the baby well?" (P5, FG1, line 364)

However, in both focus groups, participants identified that they found positives and gained experience with each child or young person they cared for at end of life. They identified how improved knowledge and understanding gave them confidence in their future care, whether this be gained from experience in practice or education beforehand.

"I mean they made me watch a YouTube video and it was how they prepare a body and that was really helpful to watch as well. Sort of gave you insight." (P8, FG2, line 532)

The Value of Support

In both focus groups, participants reported varying experiences of support. Examples were given of times when support was excellent and when the student had little or no support following the death of a child or young person. In focus group 1, participants identified that practice areas which saw a lot of planned end-of-life care, were often poorer at offering student support, where areas that experienced sudden or unexpected deaths, utilised more debriefs and formal support methods.

"I feel like the ward I was on kind of, there wasn't a whole lot of support... There was a lot of death just in general." (P2, FG1, line 214).

It was identified that the more comfortable a student felt with their colleagues or university tutors, the more likely they were to access them for support. Participants also identified that the location of the support they sought differed. If the practice area allowed, students often initially sought support from colleagues in the practice area. This occurred both informally, in break room chats, and formally through debriefs. All students who had been involved in a debrief reported finding it useful and those who had not felt they should have been or felt they would have liked to be.

“They went through the whole history they've got from mum. What had happened when the ambulance got there, what had happened when they got to resus... Like they went round everyone and said oh, you did this really well, like this worked really well... And they even included us as students as well and asked how do you think it went and said, oh, you were really good with the family, oh and your time keeping was really helpful so it's nice to be included in that and not just sit there as an observer kind of thing.” (P3, FG1, line 168).

If some time had passed since the end-of-life experience, or the student didn't feel comfortable in seeking support from their practice area, participants then chose to use their peers or tutors in university for pastoral support. Participants also reflected that they felt there was insufficient support available for healthcare staff working at all levels, who care for CYP at end of life.

“I think you're just expected to bounce back as nurses, 'cause that you've had all this training and you should be trained, but it doesn't make it any easier. So, I feel like there should be more support put in place with staff and for students.” (P7, FG2, line 338).

It was also identified by a participant in focus group 1 that some staff tried to protect student nurses from experiencing patient distress during end of life care, however, the student felt they were then missing an important experience.

“ We [student nurses] weren't allowed in the room...But then you're taking away that experience because I haven't really dealt with that before... I thought, well, if you allowed us to kind of see... because I might never see that again until I'm qualified.” (P9, FG2, line 158)

Discussion

Children's nursing students feeling unprepared to care for a CYP at end of life agrees with findings from studies focusing on both nursing students and qualified children's nurses (Pearson, 2013; Anderson et al, 2014; Kellogg et al, 2014; Heise et al, 2018). Pearson (2013) also identified that qualified nurses reported communication with the family as the hardest skill in end-of-life care, whilst Bian et al (2023) found that nurses had a 'fear of communication' with families of CYP at end of life. However, this communication is identified to be a key component of effective end of life care (Bergsträsser et al, 2017). The literature also supports the identified need for improved education around end-of-life care for nursing students (Pearson, 2013; Heise et al, 2018; Sherin et al, 2019).

Aligning with our findings, Anderson et al (2014) identified that nurses described certain patient deaths as being more significant than others and Pearson (2013) found that attachments to families were more intense if the nurses had known the families for a long period of time. Bian et al (2023) also reported long term impact and changes in life attitudes following experiences caring for CYP at end of life. However, our finding that student nurses found caring for CYP more difficult when they knew the child and felt invested in their care is at odds with the findings of Plante and Cyr (2011) who found that relationships with the patient and family did not correlate with higher intensity of grief in qualified nurses.

Many of the coping mechanisms of student nurses such as discussing the patient with peers, seeking support from peers with common experience, exploring the situation in a debrief and talking about their emotional response were similar to those reported by qualified nurses (Plante and Cyr, 2011; Stayer and Lockhart, 2016; Chew et al, 2020). Recognising the grief of the student and the need to maintain professionalism due to overarching concerns for the patient and family, their sadness and pain is in line with evidence from qualified nurses (Bergsträsser et al, 2017; Santos et al, 2020).

The need for improved support for nurses caring for CYP at the end of life is supported in studies involving of qualified nurses (Pearson, 2013; Bergsträsser et al, 2017; Muskat et al, 2020). Gorchs-Font et al (2020) identified student nurse or qualified nurses' 'right to mourn', who also found that nurses felt that they were not permitted to mourn their patients. Although some students discussed meetings held by clinical teams following the death of a child the purpose of these meetings appeared to be unclear to students, which again supports the need for improved education for nursing students (Pearson, 2013; Heise et al, 2018; Sherin et al, 2019).

Referring back to the aims of the study, this research aimed to understand the lived experiences of children's nursing students who have cared for a patient at, during, or immediately following end-of-life. This included the emotions experienced and the perceptions of support and educational needs. The study presents a range of experiences of students who highlight the value of kind, thoughtful support from the nurses they work with in practice placements. Students discussed a range of emotions from those that took the experience in stride to those that have had enduring grief and sadness. The concept of a hierarchy of grief, as perceived by student nurses and nurses themselves, warrants further investigation. Further understanding may allow for additional support in the future.

Limitations

Some limitations are recognised within the study. As the participants were recruited from a single university, and no first-year students chose to participate, this does limit the transferability. In the future we intend to conduct a regional study to build on this work, seeking wider participation. The researchers conducting the study were also part of the students teaching team, which may have had a positive impact in that the students felt comfortable in sharing experiences yet could also have had a limiting effect.

Recommendations and Considerations for Practice

This research has implications for practice internationally as educators providing nursing education, both in higher education and in practice areas, need to move beyond any notions of protecting students from the idea of death in children and young people's nursing. It is recognised by students as a sad but important part of the job role and students would prefer to be prepared with an awareness of the practical aspects of caring for CYP at end of life. Education should be introduced early, encompassing practical approaches to the varied nature of end-of-life care, normalising a range of emotions and delayed responses.

These findings demonstrate that experiences of caring for CYP at the end of life can have a lasting impact on student nurses. As such, improved support is required for both student nurses and qualified staff, who are supporting students caring for CYP at the end of life, in order to mitigate any negative ongoing influence.

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Table 1.0 student participants per year group

	Year 1	Year 2	Year 3
Focus group 1	0	0	5
Focus group 2	0	3	1
Total	0	3	6

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Table 2.0 Themes

Theme	Evidence from quotes:
Emotional practice	P6 (FG2, line 111) "this child got a new life and then the next thing I came in, the week later and it's the complete opposite... your emotions go from one extreme to the other."
The heart of the care	P9 (FG2, line 381) "Not that I wanted him to die but seeing him suffer was worse."
A lasting impact	P5 (FG1, line 140) "So I sat with him for a night shift... [it] was that one, like the one that's proper stuck with is [me]."
Hierarchy of grief	P8 (FG2, line 236) – "also at the same time my mentor was always saying to me. It's their time to grieve, not ours"
Experience, knowledge and understanding	P5 (FG1, line 365) "Oh yeah, a kid, got withdrawn and I'm like what does withdrawing mean? When I first started, like what does that mean? What happened to the baby?"
The value of support	P8 (FG2, line 283) – "My mentor to be fair she was so good. She was really in depth explaining so this has just happened, this is gonna happen next and was really structured in telling me what was happening."

Highlights:

Experiences of Nursing Students Providing End of Life Care for Children and Young People: A Focus Group Study.

- Student nurses may experience a hierarchy of grief during end of life care whereby their own feelings are unvalidated.
- The impact and intensity of grief after the death of a patient can be unpredictable, ranging from minimal to long-lasting impact.
- Recognition from nursing staff of students' care validates their experience and grief.
- Maintaining the child or young person and their family at the heart of the care proves an emotional and challenging but essential role for student nurses.
- Student nurses require enhanced education and support to enable them to effectively care for Children and Young People at the end of life.