

***“A stressful and frightening experience”?* Children’s nurses’ perceived readiness to care for children with cancer following pre-registration nurse education: A qualitative study**

ABSTRACT

Background

In the UK children with cancer are cared for by children’s nurses in a variety of settings, specialist and non-specialist. Whilst post-registration specialist education is available to some nurses, many nurses rely solely on pre-registration education to competently care for these children. This study explores whether nurses perceive that this adequately prepares them.

Objectives

To explore the extent to which qualified nurses perceive that pre-registration nurse education prepares them to care for children with cancer; to consider the implications for children’s nursing pre-registration curricula.

Design

A small-scale qualitative study was undertaken using an interpretivist approach.

Methods

Semi-structured interviews were conducted with six qualified children’s nurses in two clinical areas - a specialist children’s cancer inpatient ward, and a general children’s ward where inpatients included children with cancer.

Results

Findings are discussed in relation to three emergent themes: Learning in Theory and Practice, Care of the Child and Family, and Resilience. Participants attached significance to the quantity and quality of practice experience. They reflected on barriers to specific and transferable theoretical learning and stressed the importance of integrating theory and practice. Understanding of family-centred care formed a significant part of their preparation. Preconceptions, communication with families and the emotional impact of this speciality were stressful. Improved pre-registration preparation may have developed participants’ resilience.

Conclusion

The complexities of caring for children with cancer and their families require well-prepared nurses. Participants’ perceptions of preparedness were influenced by aspects of pre-registration education. Their experiences suggest that curricula should be practice-focused and include a range of placements. Specialist theoretical content must be integrated with practice and transferability of knowledge and skills made explicit. Reflection and problem-based learning may foster coping mechanisms and resilience that will equip them to care for children with cancer.

Key Words

Children, cancer, pre-registration, curricula, specialist.

INTRODUCTION

Reflecting on her first experiences of caring for a child with cancer in the 1950s, Thompson (2004:xi) writes: *“As nurses we were left caring for children with cancer without adequate knowledge and specific training, and this resulted in a stressful and frightening experience”*. Since then children’s nursing has developed, as have treatments of childhood cancers (Thompson, 2004) and nurse education has changed dramatically (Royal College of Nursing (RCN), 2012). Consideration of the potential impact of these changes on children’s nurses’ perceptions about their readiness to care for children with cancer is thus opportune.

Although childhood cancer is rare, cancer accounts for 20% of deaths in children and the incidence of childhood cancer within the UK has increased by over 40% since the 1960s (Cancer Research UK, 2015). Nurses care for an increasing number of these children and provide care in a wide range of settings. Every child diagnosed with cancer in the UK is allocated to a principal treatment centre (PTC); here their care is co-ordinated by a specialist team delivering complex treatment. Each child is also assigned to a paediatric oncology shared care unit (POSCU) at a hospital closer to their home which manages the child’s supportive care (NHS England, 2013). Nurses at both specialist and general paediatric wards care for these children.

In the UK pre-registration nurse education is divided into four fields of practice (adult, mental health, learning disability, and children’s) and is governed by the Nursing and Midwifery Council (NMC). The NMC sets standards for education (most recently in 2010) and all NMC-approved Higher Education Institutions (HEIs) must deliver programmes according to these standards. However, HEIs have flexibility in curriculum design (RCN, 2012), so students will qualify with varying experiences of practice and theory.

It has been claimed that specialist areas such as paediatric oncology require specialist nurses (Gibson and Hooker 2004). Similarly, Hunt (2004) states that becoming a specialist nurse requires experience and post-registration education. The Willis Commission (RCN, 2012) asserts that nurse education must be driven by the population’s health needs and the increasing incidence of childhood cancer suggests that many nurses from POSCUs and junior nurses at PTCs who lack post-registration experience and education, rely on pre-registration education to competently care for these children. In this study we seek to establish whether nurses perceive that pre-registration education adequately addresses National Institute for Health and Care Excellence (NICE 2014) requirements for healthcare practitioners involved in caring for children with cancer to have adequate training.

BACKGROUND LITERATURE

UK literature, policies and guidelines largely focus on nurse education for children with cancer that is provided at post-registration level. Most literature relating to cancer education at pre-registration level is non-UK based so needs to be interpreted with the understanding that nursing curricula vary internationally. Findings from these studies are unlikely to be generalisable to UK pre-registration curricula. However, the literature highlights interesting issues related to this topic.

Practice / Theory Learning

The NMC (2010) states that learning must be equally divided between theory and practice. With regards to theory, O'Connor and Fitzsimmons (2005) and Tomlinson (2004) discuss the inconsistency of theoretical cancer content between UK HEIs. Only Tomlinson's article focuses on children's nursing (and even here the research focuses on post-registration education) but she does highlight that qualified nurses believe that more cancer content in pre-registration programmes would have helped their preparedness. Two studies (Dean et al 2013 and Vioral 2011) conclude that students who gained practice experience were better prepared for a career in cancer nursing. Others suggest that oncology practice experiences should run concurrently alongside theoretical content (Savopoulou 2001), and that practice is needed to consolidate theoretical learning (Musgrave 1997). This sentiment supports the NMC's requirement that theory and practice learning must be integrated (NMC 2010).

Generalist versus Specialist

On-going controversy is woven throughout the literature regarding whether pre-registration nurse education should be preparing generalist or specialist nurses, and whether there is a place for learning about care of children with cancer within curricula. The NMC (2010) notes that newly qualified nurses cannot be expected to have specialist expertise, whilst acknowledging that nurse education must respond to changes in healthcare. Several studies suggest that increasing rates of cancer indicate a need for a more prepared nursing workforce (Lockhart et al 2013, Savopoulou 2001, Hermann et al 2008 and Mast 2000), but there is recognition that there are many competing curricular demands which limit the depth to which any speciality can be studied (Longman et al 1988 and Lockhart et al 2013). This has led to suggestions for incorporating specialist cancer care knowledge in a generic care context by developing transferrable knowledge and skills (Tomlinson, 2004), but it remains unclear whether this prepares nurses adequately.

Stress

Stress associated with cancer nursing is explored by many including Rushton (1999) and O'Connor and Fitzsimmons (2005) who suggest that students may hear myths and misinformation about cancer care that are not dispelled without appropriate education. Mast (2000) and Tomlinson (2004) similarly argue that stress is caused by the complexity of oncology nursing; they suggest that improved education may reduce stress experienced by cancer nursing and misunderstandings about it.

No research has been found that specifically explores the extent to which nurses feel that their pre-registration education prepares them to care for children with cancer which is the aim of this study.

METHODS

Design

A small-scale qualitative research project was undertaken to investigate whether nurses *perceive* that they are prepared, with an underlying concern that their confidence and experience may be affected by their perceptions. A qualitative design was chosen to enable participants to express their interpretations.

Participants

Participants were purposively sampled qualified children's nurses who had cared for children with cancer. They were recruited from a PTC and a POSCU. Involving both groups augmented the diversity of nursing practice and educational experiences. Also, participant inclusion was not limited by date of qualification or the HEI at which participants had studied (provided it was within the UK).

Data Collection

Face-to-face semi-structured interviews were conducted. A pilot interview and relevant literature aided the development of an interview guide which was used flexibly throughout. Interviews lasted between 30 – 60 minutes and were audio-recorded.

Ethical Considerations

Approval was obtained from a university research ethics committee and Research and Development Committees at the NHS Trusts. Letters of invitation and participant information sheets were sent to ward managers who were asked to disseminate these to staff who fitted the inclusion criteria. Written informed consent was obtained from all participants at interview. Participants have been allocated pseudonyms for confidentiality.

Data Analysis

Thematic analysis was undertaken adopting Braun and Clarke's (2006) 6-phase guide. An inductive approach was taken to coding the data where identification of codes was driven by the content of the data (Braun and Clarke 2006). A coding framework was developed on the basis of reflexive discussion about the initial coding, and the data re-coded according to the framework. Analysis by EJ using the coding framework resulted in three themes when grouped. The thematic analysis was read by both authors, discussed with TF and finally refined by EJ.

FINDINGS AND DISCUSSION

Six qualified children's nurses were interviewed, three each from the POSCU and the PTC. They had undertaken children's nurse education at five different HEIs between 2 – 27 years previously.

Three themes emerged from data analysis:

(1) *Learning in Theory and Practice*

(2) *Care of the Child and Family*

(3) *Resilience*

(1) Learning in Theory and Practice

All participants recognised that both theory and practice were important in preparing them to care for children with cancer. The amount of practice relevant to caring for children with cancer that participants had experienced was variable and this was of significance. Lauren, who had most experience of caring for children with cancer as a student, talked positively about how this had helped to prepare her. Similarly, Sophie talked about practice as a powerful way to consolidate learning. Conversely there was a significant impact for those participants who felt that they had had inadequate practice exposure to this patient group. Due to the nature of Ellie's placement (where children with cancer were usually immediately transferred to a tertiary unit) she felt that cancer care was *"always quite a bit of a mystery"*, and Samuel felt that his overall education relating to nursing care of children with cancer was significantly undermined by not having relevant practice experience.

The literature recognises the importance of practice experience in order to prepare nurses (Coyne and Needham, 2012; Musgrave, 1997; Savopoulou, 2001) and this study shows that this was significant for nurses' perceptions of their preparedness. However, it seems that the type of placement also influenced this. It has been highlighted that students need awareness of the range of settings in which cancer care is delivered (O'Connor and Fitzsimmons 2005, Mast 2000 and Savopoulou 2001) - Lauren felt that this was important and suggested that a range of placements following patient pathways would have helped:

"we liaise so much with community teams...I think if I'd had more experience in that, then maybe we'd be able to communicate and liaise better".

The quality of these placements is also crucial (NMC, 2010; Willis, 2015) and for the participants this was influenced by the mentorship they received. Sophie and Lauren spoke very positively about their specialist placement experiences. However, those with non-specialist placements voiced

concerns that mentors had prevented student involvement with the care of these children. The participants suggested a variety of explanations for this:

"[the mentors] didn't get enough experience so they needed to use the experience themselves rather than us having the opportunity" (Ellie)

However, Sarah felt that this happened for two reasons:

"everybody thought that they were the sickest ones so it was the nurses who had been qualified for a longer period of time, those that had the experience"

"we were so worried about infection... so they wouldn't have taken you as a student with them because you were a risk factor"

This had a big impact on these participants with Ellie suggesting that qualified nurses' anxieties *"cascaded down a little bit"* and Ruth saying that being distanced from the patients made children with cancer seem an *"unknown entity... it made you a bit more nervous about being round them"* It is recognised that quality of mentorship affects students' learning experiences and that mentors' levels of knowledge contribute to this (Foster et al, 2015). It has also been noted that children's nurses working in POSCUs commonly feel anxious about caring for children with cancer (Bulley 2000), but the impact of this on student nurses does not seem to have been considered.

Participants discussed the importance of learning about cancer care in theory but felt that there had been barriers to this. Few could remember learning specifically about cancer during pre-registration education. This may have been because it was excluded from curricula, and participants acknowledged that there was insufficient time to cover everything. However, it may have been because students did not remember the material. Several reflected that they were unlikely to remember content unless it was applied to practice. Samuel suggested that cancer care teaching should be delivered by experienced professionals who could describe the reality of caring for children with cancer. Similarly, Lauren suggested sessions involving families and children who had experienced cancer so students could meaningfully link theory and practice. This supports Willis' (2015) suggestion to involve service users in delivering pre-registration education.

Participants were unanimous in feeling more prepared with more theoretical knowledge, while acknowledging the transferable nature of knowledge and skills (including family-centred care, nutrition, patient assessment, pain management, infection control, central venous line care, death and dying). They felt that elements that would have helped them feel better prepared were specific to cancer care (including treatment and side effects, communicating with children with cancer and their families, and management of febrile neutropenia).

Some participants discussed the complexity of caring for children with cancer. They felt that to provide best, safe care they needed a deeper understanding of oncology which could not be reduced to a specific list of knowledge and skills. This strongly impacted on their sense of confidence:

“it was a bit scary, because I didn’t really know... If something was outside a parameter, I had no idea, I couldn’t make any decisions... it was quite disabling” (Ellie)

This complexity was exaggerated by terminology, which made transferability of knowledge and skills more difficult:

“I didn’t know why they were febrile or they were neutropaenic, or what any of it really meant... It’s got its own language, oncology” (Ellie)

Despite these complexities participants strongly valued fundamental care, echoing significant UK publications (Francis, 2013; NMC, 2010; Willis, 2015). Reassuringly this was an aspect that they did feel was transferable:

“I pre-empted it to be so much more difficult than it was, when I found out that actually the basics of cancer care was what I’d already been doing, it was a little bit easier” (Samuel)

(2) Care of the Child and Family

Participants felt that the ability to deliver family-centred care was strongly transferable. This underlying philosophy of children’s nursing is based on the premise that to provide best care to a child, the needs of the whole family must be considered (Tallon et al, 2015). Participants discussed drawing on their understanding of this from their pre-registration education and how it had helped them to care for these children and families. Family-centred care was integral to cancer care for the participants and they felt that oncology was an area that truly demonstrated its importance. This is a strength of children’s nursing pre-registration curricula.

The partnership model of care, outlining that care should be negotiated between the nurse, child and parent and allowing the child and parent to actively participate in their care needs (Casey 1988) is widely accepted UK practice (RCN, 1996). It is particularly embedded in children’s cancer care (Bulley, 2000) with parents supported to learn about their child’s condition and many of the technical skills required to care for them. Participants felt that their pre-registration education had given them understanding of this:

“[it] was always drummed in to you... the parent knows the child better” (Sarah)

However, there was consensus that the level of expertise in these families was extremely high, which was a source of anxiety:

“it is a bit scary... They are experts... and they do know more than us” (Ruth)

The expertise of families reinforced to participants that they were far from being experts themselves and Bulley (2000) notes that this disparity in knowledge can lead to nurses feeling intimidated by parents. Casey (2008) suggests that the success of the partnership model is dependent on parents' and staff communicating and working together effectively. Feelings of anxiety amongst newly qualified nurses are not conducive to this model but as participants gained more experience they became more accepting of the parents' expertise:

"As I got more experienced I was more confident to say that I didn't necessarily know" (Ellie)

According to Kirk and Glendinning (2002), not only was it helpful for nurses to gain this acceptance, but parents felt that relationships were more egalitarian if nurses were honest about their limitations. Newly qualified nurses need more support in acknowledging their lack of expertise. Benner (1982) suggests that newly qualified nurses are 'advanced beginners' in the 5 step journey from novice to expert but it has been suggested that those working in paediatric oncology actually revert to being novices (The RCN Paediatric Oncology Nursing Forum 2000). It is interesting that it is not until nurses gain experience, and reach the 'competent' stage, that they feel comfortable recognising that they do not have to know everything. This is challenging for junior nurses and they need to be equipped with greater understanding of these concepts at pre-registration level to have more realistic expectations of themselves.

(3) Resilience

Cancer care is considered stressful (Cunningham et al, 2006; Mast, 2000; O'Connor and Fitzsimmons, 2005; Rushton, 1999; Tomlinson, 2004). Themes (1) and (2) highlight that a lack of knowledge, understanding and confidence engenders stress while more preparation at pre-registration level can reduce this to an extent. Participants discussed other causes of stress, the following consideration of which will illuminate how resilience and coping strategies can be developed during pre-registration education.

Most participants discussed how their imagination of children with cancer had been a source of stress for them prior to their first experience, which in some cases had been quite shocking. Participants talked about children's appearance being altered by nasogastric tubes and alopecia; they suggested that exposure to this in a supportive environment when a student would have been helpful. However, they also talked about their expectations having been influenced by preconceptions. Rushton (1999) and O'Connor and Fitzsimmons (2005) discuss the misconceptions that people may have about cancer, as did interview narratives:

“I was prepared to see it as you see it on TV, where there’s lots of very upset families... When I turned up and it was a jovial sort of environment, it helped me settle in a bit easier”

(Samuel)

This study provides evidence that *“Education is the key to dispelling myths and misconceptions”* as asserted by Rushton (1999:78). Lauren talked about challenging her preconceptions during her placement, whereas Samuel had to face this anxiety as a qualified nurse. Improved pre-registration preparation for children’s cancer care could positively influence nurses’ expectations and alleviate some stress.

Communication with children and families was described by all participants as difficult and stressful. They talked about this both in terms of everyday communication and of breaking bad news and its aftermath. Discussing everyday communication, participants felt that they hadn’t known how to talk to the parents or children and found it difficult to empathise. Sophie felt that this had been something that had not been adequately covered during her pre-registration education whilst acknowledging that it perhaps was something that could not be learned in a theoretical way.

However, it seemed that participants had been helped by their experiences of communicating with families and children on placements, even if these had been limited:

“Although you were only going to do obs, it did help because you did go and speak to them”

(Ruth)

Participants similarly found placements helpful preparation for the reality of breaking bad news. Ellie was able to transfer knowledge and skills gained from her hospice placement to the care that she provided once qualified:

“I had the opportunity to talk openly with a lot of parents ... how they preferred to be spoken to, and how they preferred to be told... that experience that I got as a student has massively directed how I work with families as a qualified nurse”

It is acknowledged that stress is caused for nurses when bad news is given to families (Bulley 2000) and although Lauren felt that she had been comfortable with everyday communication, she found communicating with families after they had received bad news much more challenging. This is an area that is commonly not given enough attention at pre or post-registration level according to Crawford et al (2013) and the RCN (2013) have written about the essential need to equip pre-registration students with relevant communication skills suggesting that they are developed in specialist placement areas, theoretical sessions and practical, simulation sessions. Samuel, Sarah and Lauren felt that the most effective way to develop communication skills would be to have families

talk to students about their stories and journeys, and Ruth felt that a communication skills session had been useful and should be employed for other students.

Participants talked about the emotional turmoil that they experienced when caring for these children:

“It’s so intensive because you’ve got the parents emotions... you’ve got the side effects the patients are going through... It took a lot of my energy to get through every day working on that ward when I was first on there” (Samuel)

It is widely acknowledged that cancer care is emotionally challenging and this can lead to emotional exhaustion and burnout (Bulley, 2000; Zander et al, 2010). Coping mechanisms and resilience are necessary to overcome this. Both Bulley (2000) and Zander et al (2010) suggest that experience is necessary in order to develop these coping mechanisms but the latter also argue that some elements of the coping process include the ability to be reflective and use problem-solving techniques. Reflection and problem-based learning are commonly used in pre-registration education and whilst these are not a substitute for experience they may provide helpful strategies to equip nurses with coping strategies and develop their resilience (McAllister and McKinnon, 2008; Monteverde, 2014; Richez, 2014).

LIMITATIONS

None of the participants were educated under the current NMC standards (2010). The first cohort of students to graduate under these standards only completed their course in 2014 and recruitment to the study would have foundered if restricted to these nurses. It cannot be assumed that nurses would have the same educational experiences under the current standards as the study's participants. However, these standards are regularly revised and therefore the findings of this study should be considered at their next revision.

CONCLUSION

The complexities of caring for children with cancer and their families require nurses to be well prepared. It is clear that all participants in this study were able to draw on elements of their pre-registration education when caring for these families to varying extents. However, there are many aspects of cancer care that provoke anxiety and lack of confidence, which could be alleviated by adapting pre-registration curricula.

Clinical placements are fundamental in this preparation. Therefore, curricula should be practice-focused and offer various placements with supportive learning environments. It may not be feasible for all pre-registration students to experience caring for children with cancer but this should be attempted. Mentorship must be skilful and sensitive to ensure effective practice learning; further research is recommended to investigate mentors' confidence in their ability to facilitate student learning about caring for children with cancer.

Theoretical cancer care content needs to be meaningful to students and integrated with practice. Inviting service users and expert practitioners to deliver oncology sessions can provide an effective strategy. Family-centred care is well embedded into current children's nursing curricula and is perceived as transferable to this speciality. Transferability of other knowledge and skills needs to be made equally explicit to pre-registration students. Additionally, learning strategies including reflection and problem-based learning can help students to develop coping mechanisms and resilience that will better prepare them to care for children with cancer.

This study opened with a reflection that nursing children with cancer had been a "*stressful and frightening experience*" (Thompson 2004:xi). This research demonstrates that it can still be a stressful experience for nurses; we have explored the reasons for this related to education and suggested how pre-registration could better prepare nurses in future.

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