PERSPECTIVES IN PAEDIATRIC ONCOLOGY NURSING

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Perspectives in Paediatric Oncology Nursing
Contents

Foreword  Fiona Smith  ix
Preface  xi
Contributors  xvii

PART 1  PERSPECTIVES ON EDUCATION  1

Helen Langton

Chapter 1  Defining a framework for advancing clinical practice  5
Faith Gibson and Louise Hooker

Chapter 2  Specialist nurse: identified professional role or personal agenda?  28
Jane Hunt

Chapter 3  The development of nursing roles in a day-care setting  46
Louise Soanes, Karen Bravery, Julie Bayliss, Faith Gibson and Emmie Parsons

Chapter 4  Developing clinical competencies  69
Faith Gibson and Louise Soanes
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td><strong>PEACE: paediatric education, active contribution, evolution</strong></td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>Julianne Hall, Wilma Stuart and Louise Soanes</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td><strong>Developing roles in paediatric oncology: a case study</strong></td>
<td>96</td>
</tr>
<tr>
<td></td>
<td>Monica Hopkins and Karen Selwood</td>
<td></td>
</tr>
<tr>
<td><strong>PART 2</strong></td>
<td><strong>PERSPECTIVES ON THE SERVICE</strong></td>
<td>113</td>
</tr>
<tr>
<td></td>
<td>Janet Williss</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td><strong>Setting up an adolescent service</strong></td>
<td>119</td>
</tr>
<tr>
<td></td>
<td>Sue Morgan and Diane Hubber</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td><strong>Semen collection in adolescents with cancer</strong></td>
<td>141</td>
</tr>
<tr>
<td></td>
<td>Neil Shaw, Howard Wilford and Beth Sepion</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td><strong>Teenagers’ information needs</strong></td>
<td>158</td>
</tr>
<tr>
<td></td>
<td>Louise Hooker</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td><strong>Shared care</strong></td>
<td>176</td>
</tr>
<tr>
<td></td>
<td>Beth Sepion</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td><strong>A survey of staffing levels</strong></td>
<td>192</td>
</tr>
<tr>
<td></td>
<td>Rachel Hollis, Alison Arnfield and Guy Makin</td>
<td></td>
</tr>
<tr>
<td><strong>PART 3</strong></td>
<td><strong>PERSPECTIVES ON CARE</strong></td>
<td>209</td>
</tr>
<tr>
<td></td>
<td>Tom Devine</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td><strong>A Delphi survey: establishing nursing research priorities</strong></td>
<td>215</td>
</tr>
<tr>
<td></td>
<td>Louise Soanes, Faith Gibson, Julie Bayliss and Julia Hannan</td>
<td></td>
</tr>
<tr>
<td>Chapter</td>
<td>Title</td>
<td>Page</td>
</tr>
<tr>
<td>-----------</td>
<td>----------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>13</td>
<td>Development of an oral care protocol</td>
<td>237</td>
</tr>
<tr>
<td></td>
<td>Faith Gibson and Sharon Hayden</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Cancer-related fatigue in teenagers: a journey of discovery</td>
<td>261</td>
</tr>
<tr>
<td></td>
<td>Jackie Edwards, Faith Gibson and Beth Sepion</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>The experience of children with a central venous catheter</td>
<td>283</td>
</tr>
<tr>
<td></td>
<td>Linda Sanderson</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Disease and treatment-related distress among children aged 4-7 years: parent and nurse perceptions</td>
<td>311</td>
</tr>
<tr>
<td></td>
<td>Mariann Hedström and Louise von Essen</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Parental home administration of cytosine chemotherapy</td>
<td>327</td>
</tr>
<tr>
<td></td>
<td>Pippa Chesterfield</td>
<td></td>
</tr>
</tbody>
</table>

Index 347
This book brings together a unique body of knowledge about paediatric oncology nursing, charting developments, reflecting on the past and providing inspiration for the future. Paediatric oncology nursing has developed considerably over the last 20 years, with nurses leading and influencing both national and international policy and practice. Today nurses participate as equal members of the team providing care to children and young people with cancer, leading service provision, education programmes and research activities across the specialty.

The book is divided into 3 parts. Part 1 offers a perspective on education highlighting the crucial role of education to underpin clinical developments, role expansion and new ways of thinking and doing. The lack of specific education in many instances has acted as a key inhibitor preventing nurses from pushing the boundaries of their practice. Part 2 provides an insight into service provision, highlighting initiatives introduced to improve children’s, young people’s and families’ experiences. In particular the needs of young people with cancer are acknowledged as often being overlooked by service providers. Part 3 considers current perspectives in paediatric oncology nursing practice, it includes chapters on various research studies, and emphasises the importance of facilitating practitioners to develop critical appraisal skills and expertise in undertaking research so as to provide the best possible care for children and young people.

The text clearly highlights the challenges for nursing leaders and practitioners within the field of paediatric oncology over the coming months and years. Undoubtedly there is a clear need for an agreed definition of future roles in paediatric oncology nursing, along with associated competencies. The plethora of roles and titles, without consistency in local application confuses not only other colleagues but children and their families as well. Meeting the needs of young people with cancer will continue to be a challenge for practitioners and managers alike. The future is likely to see new models of service provision and nurse leaders should be

Foreword
Fiona Smith
active in determining the shape of services to meet the specialist needs of their client group. The need to address mechanisms to enable practitioners to access education programmes to acquire specialist skills and knowledge to support clinical developments is also a key challenge, particularly in view of today’s time pressures and workforce constraints. Of vital importance is the need clearly to demonstrate the impact that skilled nursing care has upon outcomes for the child or young person with cancer, as well as their family. The need for more in-depth clinically focused research cannot be over emphasised, particularly as future resources and services will undoubtedly be influenced by the available evidence to underpin decision-making. Practitioners must therefore recognise that developing research skills and knowledge is vital for the future, with research activities being seen by managers and others as a central component of clinical practice.

Lateral thinking and the development of a cohesive vision will be crucial to meet these challenges. This will entail even closer working between managers, practitioners and educators, as well as working in partnership with children, young people and their families to identify and promote best practice.

It was a pleasure to be invited to write this foreword and to have the opportunity to acknowledge the immense contribution the editors and authors have made over the years not only to paediatric oncology nursing, but to the entire field of children's nursing. It is only due to their undoubted commitment and enthusiasm that initiatives and developments have occurred.

Fiona Smith
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Preface

Personal reflections on the development of paediatric oncology nursing as a specialty

As a retired paediatric oncology nurse, I felt that the experiences and knowledge I have accrued and the changes I have witnessed as a nurse over the past four decades have provided me with sufficient material to offer a personal perspective on the development of paediatric oncology nursing, as an introduction to this textbook. Putting this narrative together has given me time to reflect on the challenges, resources and rewards encountered as the specialty has developed. As I have identified the significant changes in the treatment and care of childhood cancer, it was interesting to note the differences and similarities in nursing practice over the past four decades.

My first encounter with caring for a child with leukaemia was during a paediatric placement while in training as a general nurse in the late 1950s. In the 1950s to 1960s there were no major technological advances in the management of childhood cancer, apart from some attempts at drug therapy and limited use of radiotherapy for symptom control. At this time treatment generally consisted of steroid medication and blood transfusions. From a nursing perspective, I felt totally unprepared, with little knowledge about how to care for the child and family receiving cancer therapies. I would sit with a child and, when the family visited, I would also spend time with them. However, I was unable to answer their questions. Even if I had known the answer I could not have helped them, because the policy at that time was that only medical staff could offer information. Parents and family members of a very sick child were given special ‘open visiting’ status. Other families were restricted to visiting times. This was because childhood cancer was then viewed as a terminal illness. There was little or no acknowledgement of the need to prepare the child or the child’s family for that death. 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. I was ill-prepared to cope with all aspects of the children’s illness and at that time their inevitable death.
My experience was not, I am sure, too dissimilar to that of my medical colleagues. Although I felt inadequately prepared as a nurse in the face of caring for a dying child, I had a sense of feeling less hopeless. As a nurse I could at least provide physical and emotional support. The medical staff were unable to provide much in the way of treatment. Somehow, although frightening, it was this experience that stimulated me to train as a children’s nurse and then to choose to work with children with cancer. Thankfully much has changed since the 1970s. The advent of new diagnostic tools and treatment techniques has considerably changed the nature and course of childhood cancer. The concerns of paediatric oncologists have shifted from terminal care, to cure and survival, and hence to an increased focus on the child and family’s physical and psychological needs.

During the 1970s, I was working on a newly opened Paediatric Oncology Unit and new technology and trends in healthcare were rapidly changing. One trend that is now well established was the involvement of families in the care of the hospitalized child, with open visiting becoming the norm. Cure was now a possibility with up to 50% of children with leukaemia having a real chance of survival. Clinical trials were developing and well-conceived treatment protocols enabled treatment evaluations to be routinely undertaken. Much of this progress was as a result of a collaborative approach to studies and clinical trials coordinated locally by the United Kingdom Children’s Cancer Study Group (UKCCSG) and at a European level by the International Society of Paediatric Oncology (SIOP).

This was also a time when supportive therapy was being developed for potential and actual side effects of treatment, such as pneumocystis carinii pneumonia (PCP). However, one of the most distressing problems that existed at this time was the nausea and vomiting children experienced post-chemotherapy treatment. Attempts were made with the available antiemetics to reduce this distressing side effect. Much of my nursing time was involved with comforting the child and family through this traumatic period. Frequent re-siting of intravenous cannulae added further distress and discomfort. I recall, on certain days, that children would attend as an outpatient for combination chemotherapy treatment and then be admitted to the inpatient area for monitoring and observation. This practice of giving a number of children similar treatment on the same day, roughly at the same time, meant that most of the nursing care for most of the inpatient children was to support and comfort both the child and the family through a distressing period of nausea and vomiting. Fortunately I worked with a supportive medical team who were willing to answer my numerous questions about changing this practice to one of a more staggered admission policy. By so doing, nursing resources were better used and, as a result, patient care was improved because closer monitoring and
support for a small number of patients on different days could be accommodated.

My role and function continued to change and develop and, during the 1970s, I was involved not only in the physical care of the child but also in the mixing and administration of chemotherapy. This extension of my role also included undertaking the placement of intravenous cannulae. Training for these skills was developed ‘in house’ by committed nurse leaders. Some nurses argued that this development was nothing more than taking on doctors’ tasks. Thankfully those who were more enlightened could see the benefit to patient care by extending our expertise. This was also a time when collaboration and teamwork began to develop and the role of the nurse was strengthened as credence was given to the nurse’s contribution to the overall management: views on patient care were acknowledged and sought. Nurses at my institution and others were instrumental in the development of programmes to enable children to have painful procedures carried out under general anaesthesia. Before this development most centres were using a cocktail of sedative drugs; this combination was often ineffective for pain control and the effects left the child sleepy for the rest of the day.

This was also the time when patient and family education became a true reality and accepted as good practice. Nurses were now teaching parents about blood values and the effects of chemotherapy and other treatments on blood counts. Nurses were also beginning to look at their practice and early independent nurse research programmes were able to influence and change the way we practised. This also had an effect on the way we, and others outside the specialty, thought about childhood cancer.

One example was the work of Martinson (1976), a nurse working in North America who was instrumental in the development of home care for the dying child. Before this, children with a terminal illness would be admitted to hospital to die. In the UK, home care was slow to develop; recognition of the need was acknowledged but issues about funding and training for community staff had a detrimental effect by slowing down progress. It was also recognized that some curative treatment could be carried out in the home setting. This evolution began with the introduction of community liaison nurses who were employed to contact community staff over the telephone to advise on home care. It soon became evident that this approach to home care was less than satisfactory. Community nurses and other community staff stated that they were not sufficiently knowledgeable or did not have the clinical expertise to carry out this care without significant input from specialist nurses. Families and children with cancer were also finding that staff in the community lacked the specialist knowledge and expertise. As a result during the 1980s,
paediatric oncology outreach teams based at specialist centres were developed. Again nurses were in the forefront of discussions and seeking funds for this much needed service. Funding for these posts was and remains a mixture of NHS and charitable organizations with Cancer Macmillan taking a significant role in supporting this development.

In the 1980s, more intensive therapies were developed and nursing acknowledged the need to underpin their practice with greater in-depth knowledge and training. The first steps were taken in the UK in 1984, when a cohort of paediatric nurses working in the specialty established the Royal College of Nursing’s (RCN’s) Paediatric Oncology Nursing Forum (PONF). The first paediatric oncology nursing conference, under the auspices of the RCN, was held in 1988. Simultaneously, nurses also held their first meeting at a SIOP conference where they met with medical colleagues to discuss issues of interest. Recognition of the need for specific nurse education in the care of children with cancer, at my institution, involved the development of a short ‘in-house’ paediatric oncology nursing course. This was followed by introduction of the English National Board (ENB) course and qualification (ENB 240) in a number of specialist centres (Gibson and Langton, 1998). Before these developments clinical nurse specialist posts were being introduced. These initiatives have been a powerful force in ensuring that nurses have a strong voice in the overall care and management of children and their families. Nurses were also becoming involved with clinical research and undertaking small-scale, single-site studies looking at specific issues, often related to symptom management.

Change continued apace with nursing care becoming more challenging as therapies became more complex. Thus, time spent managing patient care increased. At this time there were several advances that had a great impact on my nursing practice and the quality of life for patients; these were the introduction of tunnelled intravenous devices and the use of 5HT3 blockers (5HT is 5-hydroxytryptamine or serotonin) for the control of nausea and vomiting. No longer were children suffering the frequent placement of intravenous cannulae and the prolonged exhausting bouts of nausea and vomiting. Nursing was still about direct patient care. However, nurses with expertise in the specialty were now involved in the administration of therapies, monitoring of side effects, and promotion of comfort and support for the child and family throughout their treatment trajectory. This included helping the child and family to understand the disease, understanding approaches to treatment, short- and long-term side effects, and care of the child at home. The use of central venous catheters, while improving the quality of life for the child on intensive regimens, increased the burden on home care and the need for further education. This
education was of major importance for the child and family and the community-based staff because more children were receiving therapy as outpatients. Children were now discharged home with catheters in situ.

Another development was that of ‘shared care’. This development has encountered many challenges, mostly related to the alleged lack of resources, expertise and knowledge of carers in the referring hospital, and the expectations of the now-empowered ‘expert parent’ and child. This situation continues to be a challenge and nurses are centrally involved in looking to resolve problems and improve collaborative relationships. This issue is addressed later in this textbook through exploration of the perceptions of parents.

In the 1990s, paediatric oncology nurses were employed in vital positions throughout the specialist centres. Educational programmes at diploma and degree level were developed to provide nurses with an academic qualification, further enabling them to take an essential role within the now established multidisciplinary team. New treatments continued to be developed and clinical trials became even more complex. The multifaceted role of the nurse working with children undergoing clinical trials involved child and family education, direct care-giving and accurate data recording. Collaboration with the UKCCSG enabled nurses to be involved in decision-making such as in the New Agents Group (NAG) and in working parties looking at specific areas of interest, e.g. child and family consent to treatment, palliative and adolescent care. In 1995, I was personally invited to be the nurse member of a working party for the Department of Health, looking at the provision and treatment of care of the child with leukaemia. This invitation left me to reflect on how much the position and status of nurses has changed since my training days. Exciting other developments were the first multiprofessional conference in collaboration with the UKCCSG and PONF, which took place in 1997, and the fact that SIOP opened its membership to nurses in 1999.

New nursing roles were also being given consideration and the role of the advanced practitioner was established. During this decade specialist nurses continued to develop sophisticated and credible programmes of nursing research. Single-site studies designed to answer short-term questions have been undertaken, because care and procedures have aspects that are unique to each care setting. However, a concern within one paediatric oncology setting is more than likely to be of concern to others, and the sharing of outcomes has influenced and supported changes in practice more than single-site studies. Examples of single-site studies are to be found in this book.

Of particular interest during this decade was the result of a study reviewing the work of the paediatric oncology outreach nursing service.
The results of this study influenced and supported the continual development of the service at all specialist centres. A number of paediatric oncology nurses have also studied at PhD level and their research work has contributed to this specialist nursing body of knowledge. As we enter a new century, paediatric oncology nurse researchers/practitioners continue to provide and explore scientifically based care. Contributions to this book provide ample evidence of how the art and the science of paediatric nursing has been taken forward and the willingness of nurses to share their concerns and experiences through publication.

It has been interesting to reflect on my perceptions on the development of paediatric oncology nursing. As a student nurse I was totally unprepared when confronted with the care of a child with leukaemia. I then moved through decades of change in both the treatment and care of the child with cancer, approaches to healthcare, and the ever-changing role and status of the nurse. What has significantly changed is that nurses educated at diploma and degree level, with a firm knowledge-based clinical role, hold a central position in the multiprofessional team. What has not changed over the course of time is the presence of the nurse at the bedside providing comfort to the child and family. This development must in part be attributed to the timeless enthusiasm, dedication and the determination of nurses in the specialty striving to deliver improved knowledge-based care for children with cancer and their families. I hope that this book helps the nurses of the future, junior and senior, to continue with this work. I have no doubts that the specialty will continue to change; reflections over the next 50 years should look equally interesting.

Jenny Thompson

References and suggested reading

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As the care of children with cancer and their families becomes ever more complex and demanding, it is apparent that the specialty of paediatric oncology nursing is exploring and pushing the boundaries of practice. Nowhere is this more apparent than in the development of new roles and new ways of thinking and doing. This book offers a timely exploration of the history and development of new roles, based on current examples from practice. The book also shares ongoing research work to underpin these developments from an evidence-based perspective. Key issues are explored in relation to the complexities of professional practice, the influence of service delivery, and the role of education in supporting and developing practice in order to offer the reader an holistic overview of current perspectives in paediatric oncology nursing.

Chapter 1 presents a framework that can be used when developing new roles in paediatric oncology and sets the scene for the following two chapters which present the development of advanced roles in clinical practice. The chapter begins by demonstrating the value of networking and the vast resource that exists in terms of knowledge base and expertise within paediatric oncology nursing. This is in no small part the result of the Royal College of Nursing Paediatric Oncology Nursing Forum and the passion that exists among the members to develop practice for the benefit of children with cancer and their families. This chapter also demonstrates the value of using existing work in order to develop practice rather than unnecessarily reinventing the wheel. The value of this chapter is in the statements that are made around how to define advanced practice and the framework offered for role development. This chapter also offers a way through the often confusing implementation of such roles with a systematic and constructive approach. Service, management and education domains are all examined and pitfalls are identified; however, pointers for the future are also given and this chapter leaves the reader feeling that there may be light at the end of the tunnel.

Chapter 2 presents a useful exploration of the history and development of specialist nurses, both generally and in relation to paediatric oncology outreach nurse specialists within local communities and regional centres.
The literature is well evaluated and several key themes emerge. The overarching dilemma facing paediatric oncology nursing is the confusion of terminology around the concept and interpretation of the specialist nurse. This is seen at a variety of levels: Government, as expressed through policy; organizational, as expressed through service delivery; and at the point of delivery of care, as seen in the way in which the title ‘specialist’ is obtained and the perception of the user – the child and family. National guidelines give rise to multiple local interpretations, thus compounding the ability of the specialty to identify clearly the way forward. This impacts on career planning and career pathways, and it becomes difficult to advise and guide nurses new into the specialty without clear interpretations of role. However, what is clearly articulated within the chapter is the need to expand practice through development of these roles and this is explored more fully in Chapter 2.

The focus of Chapter 3 is the review of a specific role – that of the nurse practitioner as applied to a specific paediatric oncology unit. Again the clear theme arising from the literature is that of confusion over the concept and interpretation of the role. This chapter presents a literature review of this role, and then outlines the process and findings of participatory action research work that was undertaken within the unit. The role is identified as arising from a number of driving forces, in particular the reduction in doctors’ hours (Greenhalgh & Co., 1994) and the need to develop career pathways for nurses (Department of Health or DoH, 1998). However, the action research demonstrated that focus on one role to the exclusion of staff development for all may be detrimental in the longer term. The chapter identifies the lack of clarity around the concept of advanced practice and is critical about the lack of education to enable development of the advanced practitioner. However, as the authors note, if there is lack of a clear concept of what an advanced practitioner is, then it is difficult to provide the right education to develop the skills required to be an advanced practitioner. This then impacts on the ability to offer clear career pathways for nurses within the specialty. The action research work did, however, demonstrate the need to develop all staff and also suggested that, in order to achieve this, a clear competency framework could be one way forward.

Chapter 4 commences with an overview of the history of competency development related to the literature regarding professionalism and the more recent debates around fitness for purpose and for practice. The authors present the difficulties surrounding the development and assessment of competency in nursing that is holistic and based on the concept of lifelong learning, using reflection in and on practice. However, the authors do not leave us frustrated with the debate but continue by presenting a tool that they have developed which identifies competencies and
how to assess them in relation to qualified nurses undertaking a paediatric oncology course that incorporates practice and development of competency. This chapter also demonstrates the use of the nominal group technique as one way to generate competencies and to involve practitioners; it also demonstrates the value of an evaluation study to promote continuing refinement of such a tool.

Chapter 5 adds to the discussions exploring the need for new roles to be underpinned by education and competence; in this chapter the authors describe an educational programme for nurses working in paediatric palliative care. The programme described here demonstrates how collaboration between educators and practitioners aids the joint development of any initiative like this, and the suggestion that both parties need to be experienced in the field of paediatric oncology nursing in order for mutual regard and smooth working.

The theme of role development is maintained in Chapter 6, the final chapter of this part. Literature again demonstrates the lack of parity of interpretation of the concept of various roles, e.g. advanced nurse practitioner and clinical nurse specialist, and the education required to underpin these practice roles. The authors outline a case study undertaken locally that arose out of a perceived gap in continuity of care and communication across the multidisciplinary team. The reduction in doctors’ working hours and the increasing complexity of care required by children with cancer and their families suggested that a detailed review of roles and education provision was required. The outcome of the review was the development of an advanced nurse practitioner role and the chapter is devoted mainly to a description of the implementation and subsequent development of the role. This chapter particularly emphasizes the clear need for relevant education to underpin the development into a role such as this which must include competencies in practice. It also emphasizes the value of the concept of teamwork if high-quality care is to be offered to users of the service. The authors comment on the lack of rigorous evaluation of the role, and indeed the development of new roles does offer an opportunity for evaluation, although it is well acknowledged that attempting to evaluate benefit to practice is difficult to achieve.

In conclusion, this part of the book offers paediatric oncology nurses the opportunity to develop insight into current thinking that is impacting on the specialty in relation to new roles and the issues that surround their development. At a national level, the profession has not agreed a clear definition of roles and this is resulting in confusion about the concept of various roles such as clinical nurse specialist, nurse/advanced nurse practitioner and nurse consultant. Furthermore, as a result of this confusion, these roles are interpreted at a service organizational level in a variety of
ways, resulting in further confusion for colleagues and, more important-
ly, for children with cancer and their families. Nursing roles are already
experienced differently by these families as they move between shared
care units, community care and the regional provider. The further intro-
duction of new roles has the distinct probability of making this worse not
better, and therefore the potential of fragmenting the patient experience,
not providing greater continuity. If the concept of the user as central to
care is to be maintained, this disparity needs to be addressed.

The value of this part of the book for paediatric oncology nurses is that,
having explored the literature and exposed the confusion, it offers readers
a framework within which to proceed when developing new roles. This
framework is timely, and offers paediatric oncology nursing the opportu-
nity to set its own house in order and to lead the way for nursing. The
outline of various models already in existence also allows readers to ben-
efit from the learning gained in these arenas and to translate this to their
own area of practice in order not to reinvent the wheel or suffer the same
pitfalls and difficulties. The advantage of paediatric oncology nursing, in
being a relatively small specialty, is in the ability to network among prac-
titioners. Readers need to capitalize on this in order to move practice
forward at a greater pace and in a more coordinated way than may be pos-
sible for others working within a larger arena. This particularly applies to
the development of competencies. Nationally, cancer networks are pro-
moting competency development and are keen not to reinvent wheels if
best practice already exists. The close relationship between the Paediatric
Oncology Nursing Forum and the Cancer Alliance may enable us to share
with each other and thus address issues together where possible. This may
also enable seamless delivery to occur nationally (DoH, 2000).

The final value is the way in which this part of the book demonstrates
the use of a wide variety of research methods and methodologies as
applied to the specialty. In this age of evidence-based practice it is encour-
gaging to see managers, practitioners and educators working together to
identify and promote best practice through the generation of evidence. It
is hoped that the reader will be motivated to explore the use of some of
these tools in their own areas of practice and, as importantly, to share
their findings.

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Paediatric oncology nurses today face challenges from both the profession itself and society to provide clinical expertise in a complex and rapidly changing specialty. Developments in the medical treatment of childhood cancer mean that the expected survival rates have never been better. Consequently, paediatric oncology nurses caring for children with cancer have had to keep pace with and respond to advances in treatment, as well as technological and service developments. The nature of the care provided in inpatient, outpatient and community settings has changed in recent years, and this change will continue, with an increasing number of children in all three settings requiring highly specialized care throughout their disease, e.g. the specialty of palliative care has grown significantly, with models of care for both children (Goldman, 1998) and adolescents in place (Edwards, 2001). In addition, long-term follow-up has become a major component of care as more children survive into adulthood (Stiller, 1994; Gibson and Soanes, 2001).

The changes that have taken place have altered the way in which healthcare is perceived and delivered. The roles involved in paediatric oncology nursing are now diverse, and offer scope for role development in direct clinical care, as well as education, management and research. In addition, there are a number of opportunities afforded by the variety of clinical specialisms within paediatric oncology, including clinical nurse specialist posts in bone marrow transplantation, care of adolescents, palliative care and intravenous therapy, to mention a few. Role development has taken place in response to changes in healthcare and local circumstances; the more recent additions of case managers and advanced nurse practitioners represent continuing innovations in the organization and delivery of care. These developments are to be welcomed if they ensure that outcomes are improved and that services continue to meet the needs of children and families. However, these changes are not without their problems, particularly
where nursing roles have evolved in an unstructured or reactive way, or where full consideration has not been given to potential consequences.

Nurses have a significant contribution to make in ensuring a cohesive service, working as they do with other colleagues and across professional and organizational boundaries (NHS Executive, 2000). Such unstructured and reactive role evolution could benefit from a proactive and robust national framework that supports individual nurses in practice expansion, and provides safeguards for their patients. One such model is referred to as a ‘safety net to support professional practice’ (Royal College of Paediatrics and Child Health/Joint British Advisory Committee on Children’s Nursing, 1996), and this has been adapted and applied to paediatric oncology nursing (Royal College of Nursing [RCN], 2000). This chapter details the approaches taken to define and develop the framework for role development in paediatric oncology nursing. It starts by setting the scene and placing role development within the context of policy and practice. The process of developing the framework is then outlined, followed by a discussion of the dimensions for role development that form the starting point in an exploration of the characteristics of paediatric oncology nurses. The framework presented is followed by an example of how it can be used in practice.

Setting the scene

The scope of paediatric oncology nursing practice

There are currently 21 United Kingdom Children’s Cancer Study Group (UKCCSG) centres in the UK and one in Eire. This approach to the organization of care gives the family of the child with cancer access to the best medical treatment, supported by specialist nursing care (Gibson and Williams, 1997). There are a number of published documents that outline the standards required to offer a quality service to children with cancer (Expert Advisory Group on Cancer, 1995; Royal College of Pathologists, 1996; UKCCSG, 1997a, 1997b), all of which refer to the need for appropriately qualified and experienced nursing staff. In all, however, there is a distinct lack of detail about the nature and training of a paediatric oncology nurse. What is known, however, is that specialist areas of practice, such as paediatric oncology, need specialist nurses.

Specialization in nursing was noted by the International Council of Nurses (ICN, 1985) to have occurred because of:

- the need for more effective use of nurses
- the changing sociological, cultural and economic factors affecting health
• advances and changes in medical practice
• the specific health needs of a population
• developing national priorities in healthcare.

The process of this development was not, however, determined in a systematic way, and was often perceived to parallel developments in the disease-focused model of medical specialities (RCN, 1988). Problems and issues with increasing specialization were recognized by the ICN, with concerns revolving around the benefits of specialization and the forces driving them. The ICN was also anxious about the qualifications of nurses working in specialist areas, and their place within the structure of the profession and the healthcare system as a whole. One of the potential outcomes, if developments were to continue in a disorderly fashion, was thought to be fragmentation of nursing care and the splintering of the profession (Styles, 1989). Dalziel (1990) reinforced the concern about these potential outcomes and advocated that nurses define the specialities in nursing before the Government and other care workers seize that opportunity and impose frameworks more reflective of a medical than a nursing model.

In response to their growing concerns, and with the express aim of assisting the profession to develop a systematic means for designating specialities, the ICN (1991) detailed 10 essential features for orderly development of a specialization. The scope of paediatric oncology nursing expresses all the features detailed by the ICN and may therefore be defined as specialist practice:

1. The specialty defines itself as nursing and subscribes to the overall purpose, functions and ethical standards of nursing. Nursing practice is distinguished by a focus on holistic care, collaboration with families within a tradition of care and concern, and an ever-growing body of nursing knowledge.

2. The specialty practice is sufficiently complex and advanced, and is beyond the scope of general nursing practice. Although cancer and cancer nursing are represented in pre-registration curricula, the level of knowledge shared, together with the limited, and for some absent, clinical practice for children's nurses, equips nurses with only a very rudimentary knowledge and understanding of the area of practice. Further knowledge and skills of this complex area of care were initially acquired 'on the job' with nurses of children with cancer learning from role models and in-house training. It was soon recognized that this, although meeting local needs, was insufficient. Post-registration programmes were therefore developed to expand specialist knowledge and skills to complement core knowledge of child health and beliefs of how to care for children with cancer and their families.
3. **There is both a demand and a need for the specialty service.** Childhood cancer is a rare disease in the UK with an incidence rate for children under 15 years of only 110–130 per million per year. The referral to regional paediatric centres ensures that families receive care from healthcare professionals who are familiar with their specific needs. The holistic requirements posed by toxic and complicated treatment regimens demands a specialist service.

4. **The focus of the specialty is a defined population, which demonstrates recurrent problems and phenomena that lie within the discipline and practice of nursing.** Nursing focuses on the effects that cancer and its various treatments have on the individual family, observing side effects and managing symptoms. There is an understanding that nurses do undertake medical work that is appropriate but within the context of nursing. The therapeutic work of nursing is being developed throughout the specialty.

5. **The specialty practice is based on a core body of nursing knowledge, which is currently being expanded and refined through research.** There are mechanisms for reviewing and disseminating research. The charting of nursing knowledge within the specialty has been slow when compared with colleagues in the USA who established the *Journal of Association of Pediatric Oncology Nurses* (JAPON) in 1984. Nevertheless a core body of nursing knowledge is now being expanded through unidisciplinary, multidisciplinary, multicentre and collaborative research. There is increasing evidence that nurses publish and disseminate their work through both popular and academic nursing and medical journals.

6. **The specialty has established educational and practice standards, which are congruent with those of the profession and are set by recognized nursing body or bodies.** In the past, the English National Board regulated education programmes and the UKCC recorded specialist education. Both of these organizations have since been superseded by the Nursing and Midwifery Council (NMC). In contrast to colleagues in the USA, who set up standards of practice in 1979 and re-affirmed them in 2000 (Association of Pediatric Oncology Nurses, 2000), there are no nationally agreed published standards in the UK. Nevertheless, standards of care in the form of guidelines are being produced and endorsed in textbooks that detail the care of children with cancer. Clinical competencies are being developed locally (Gibson and Soanes, 2000) and the need for national competencies is being addressed (Long et al., 2001).

7. **The specialty adheres to the registration requirement for the general nurse.** Registration as a children’s nurse is required as the first step to becoming a paediatric oncology nurse.

8. **Specialty expertise is obtained through a professionally approved advanced education programme, which leads to a recognized qualification.** The educational programme preparing the specialist is
administered by a nurse. The first specialist programme was a short programme developed in 1985. Longer English National Board for Nursing, Midwifery and Health Visiting (ENB) courses developed soon after to include a clinical component alongside theory (Casey, 1989). Since that time, nurse educators have introduced different and creative approaches to ongoing education. Access to core specialty knowledge for as many paediatric oncology nurses as possible has been provided through links with adult oncology courses, introduction of theory-only courses and production of short courses aimed at nurses in shared care centres (Gibson and Langton, 1998).

9. The specialty has a credentialing process determined by the profession. Registration as paediatric nurses and certification as paediatric oncology nurses are forms of credentialing.

10. Practitioners are organized and represented within a specialty association or a branch of the National Nurses’ Association. Since 1984 the Paediatric Oncology Nurses’ Forum (PONF), a forum of the RCN, has represented paediatric oncology nurses. The diverse areas of practice, such as direct clinical care, education, management and research, are represented in the Forum. It also provides a venue for communication where nurses can exchange new and alternative methods of nursing care provision, consider creative approaches to continuing education and identify a focus for research. All of these ultimately have an impact on improving the care for children and their families.

Changing the scope of nursing practice

Career opportunities have been enhanced through structured development of specialities in nursing. Since the appointment of the first infection control sister in 1974, the role of the clinical nurse specialist (CNS) in nursing specialities has grown (Tiffany, 1976; Humphris, 1994). These roles have developed from existing structures because of recognized patient need for more expert and specialized care, and by nurses who wanted to stay in a direct relationship with patients (Castledine, 1998). Specialization continues with advances in medical science and technology, resulting in a reappraisal of traditional roles within both nursing and medicine, and the boundaries between the clinical work of doctors and that of nurses being redrawn (Dowling et al., 1995). The team approach, in which doctors, nurses and other allied health professionals adapt and develop new skills, is being increasingly emphasized (English, 1997). For nurses, this has resulted in an increase in specialization, with some recent innovations clearly reflecting an expansion of the nurse’s role, often at the interface between nursing and medicine (McKee and Lessof, 1992; Autar, 1996). Some of these areas of expansion have clearly had an impact on the
workload of junior doctors; documents addressing the training of junior doctors, such as the ‘New Deal’ (NHS Management Executive, 1991) and that of Calman (1993), considered alongside the Scope of Professional Practice (UKCC, 1992), have provided tremendous opportunities and challenges to nurses in the UK (Pickersgill, 1993; Koefmann, 1995). The demise of rigid practice boundaries heralded by the ‘Scope’ document (UKCC, 1992) led to nurses taking on an increasing number of tasks, e.g. venepuncture, cervical smears, taking blood samples and ECG recordings, defibrillation, catheterization of male patients, blood glucose monitoring, etc. (UKCC, 2000). This document ended the requirement for nurses to gain certificates for each extended role and placed the responsibility for competence within expanded practice boundaries for individuals. What was not addressed by the ‘Scope’ document was, however, how decisions are made about the scope of nursing practice, the education and training required, and how expansions into practice are monitored (Wainwright, 1994). The extent to which nurses achieve authority over the nature of their practice was also not addressed by the document. Nevertheless it played a significant role in encouraging the nursing profession to consider the development of roles that would encompass the complexities of role expansion, rather than simply absorbing medical tasks (Pickersgill, 1993). Although there is no explicit link between the document and the changes in nursing in relation to role development, they cannot be viewed separately (Finlay, 2000) because it provided a set of principles that have had a significant impact on how nurses’ work is undertaken (Jowett et al., 1999). What remains, however, is some confusion about how far the expansion of nursing practice is associated with developing professional nursing practice (Bowler and Mallik, 1998; Cameron, 2000; Finlay, 2000; Woods, 2000).

**Developing new roles**

That nurses embrace the notion of role development is now implicit in a number of national strategy documents that have appeared over the last decade: A Vision for the Future (Department of Health [DoH], 1993), and The Challenges for Nursing and Midwifery in the 21st Century (The Heathrow Debate – DoH, 1994). More recently, the document Making a Difference (DoH, 1999a) has explicitly detailed a vision for how the current Government see nurses taking on more complex roles and having a greater responsibility for the delivery of patient care. A new modern career framework, linked to the Government’s proposals to modernize the NHS pay system (DoH, 1999b), was proposed in Making a Difference, suggesting that delivery of a comprehensive service required the following: health