

Paediatric Update

The role of the specialist nurse in paediatric oncology in the United Kingdom

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Abstract

National guidance in the United Kingdom on the provision of services for children and young people with cancer and their families has consistently emphasised the need for specialist nursing as central to the delivery of safe and effective care. The temptation when examining the role of the specialist nurse is to look at those posts that carry a recognised 'specialist' label. It is equally important, however, to look at the development of nursing practice across the speciality and at how this can be both supported and recognised. Nurses with specialist knowledge, skills and expertise in paediatric oncology are needed in positions where they are able to develop nursing practice, direct service development, lead nursing research, and guide education and training. Effective clinical leadership is essential at the point at which nursing care is delivered whether that is at the hospital bedside, in the clinic and day care unit, or in the family home. © 2005 Elsevier Ltd. All rights reserved.

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1. Introduction

The role of the specialist nurse in paediatric oncology is as diverse as the individuals who undertake such roles, and the settings within which they work. In paediatric oncology, nurses are faced with many challenges in a constantly changing health care environment. Advances in treatment and technology, growing expertise in patient management and multiprofessional care have all improved patient outcomes, and at the same time impacted on nursing practice. Nursing within the speciality has been affected by changes in medical training and working patterns, changes in treatment patterns, and changes within the profession itself. Nurses have taken on new roles and responsibilities, and are continuing to expand the boundaries of their practice. This has led to increased

demands on nursing at all levels of the workforce. The temptation when examining the role of the specialist nurse is to look only at those posts that carry a recognised 'specialist' label. It is instructive to look at the development of these posts, and to identify the contribution to care that they make. It is equally important, however, to look at the development of nursing practice across the speciality and how this can be both supported and recognised. Within paediatric oncology, there has been attempts to bring clarity and structure to developments to ensure that individual nurses are supported as they expand their practice, that they do so in collaboration with other members of the multidisciplinary team, and that this is always in the best interests of patients.

2. The history of nurse specialists in paediatric oncology

Nursing children and young people with cancer is a speciality within paediatric nursing that makes great de-

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mands on its practitioners. It is a speciality where multidisciplinary team working has always been one of the guiding principles, and nursing has been recognised as key to the provision of effective care. The role of specialist nurses as they have developed in the past has generally been either to meet identified gaps in service provision, or to give some form of recognition to the clinical skills, experience and expertise of individual practitioners. The largest and longest established body of nurse specialists in paediatric oncology in the UK is the Paediatric Oncology Outreach Nurse Specialists (POONS) [1]. The original impetus behind these posts, which were developed in the 1980s, often with charitable funding, was to support both families and professional carers through a child's terminal illness at home, where often there was no locally available appropriate resource [2]. Hunt has described how the success of these posts, and the improved outcomes in childhood cancer treatment, led to the national expansion of posts, and a change in emphasis, to support families throughout the child's illness, whatever the outcome, and to provide a link between primary, secondary and tertiary care [1]. The 'specialist' status awarded to these posts was frequently a reflection of the perceived expertise of the post-holders as individuals. It was derived from a mixture of formal qualifications, hands-on technical skills, extensive clinical experience within the speciality, in-depth medical knowledge, and an insight born of experience into the particular needs of children and families [1].

Following on from the success of the early outreach posts, other nurse specialist posts developed in paediatric oncology. These posts frequently developed in response to gaps in service provision, or identified areas of clinical need. Such posts were often championed by medical consultants who valued the contribution made by nursing colleagues, and wished to have it more clearly recognised. Posts often developed in an *ad hoc* and reactive way, and again were initially founded on the extensive clinical background and specialist knowledge and expertise of the individuals who undertook them.

3. The professional context

The 1980s and 1990s saw a proliferation of specialist nursing roles and titles, in response to the need for more complex and specialist care in a rapidly changing National Health Service (NHS), and the subsequent expansion of skills and knowledge in the nursing profession. Specialisation continues with advances in medical science and technology resulting in a reappraisal of traditional roles within both nursing and medicine, and a redefining of the boundaries between the clinical work of doctors, nurses and other health care professionals [3]. The importance of the multidisciplinary team in which all its members work together and develop new skills is increasingly

emphasised [4] in a health care environment where practitioners perform complementary, and often overlapping roles to solve complex patient care issues [5].

In 1992 nursing's professional body, the United Kingdom Central Council for Nursing and Midwifery (UKCC), predecessor to today's Nursing and Midwifery Council (NMC) issued a key document, the 'Scope of professional practice' which enabled nurses to expand their practice boundaries, within the limits of their own competence [6]. The NMC is currently working on the setting of agreed competencies for advanced and specialist practice roles. The UKCC, defined specialist practice in nursing as 'the exercising of higher levels of judgement, discretion and decision making in clinical care' [7]. The title of 'nurse specialist' as it has been used in the UK brings with it a range of different interpretations, with no clearly accepted definition either of a prescribed role, or of the qualifications or experience required to undertake it. This is different to the situation in North America, where roles such as 'Clinical Nurse Specialist' and 'Nurse Practitioner' have very clear definitions and expectations as to the role profile, the competencies required, and the educational preparation needed to undertake them. Although this has led to some confusion in the UK, and calls within the nursing press for consistency, it has also meant that nurses have often had the opportunity to develop roles in accordance with the needs of local services.

4. Government policy

There has been a growing recognition at the Department of Health (DOH) and in government policy of the potential of nursing in the development of services. The DOH in its key strategy document for nursing, 'Making A Difference' [8] strongly advocates the development of nursing roles as an important way of improving services. There are two key drivers in this development, the untapped potential to be unlocked in the nursing workforce, with its increasing clinical expertise, and the changes to medicine that have an impact on both the training and service elements of medical posts. The requirements of the European Working Time Directive, the subsequent reduction in junior doctor hours, and more recently the new consultant contract have all had a considerable impact on service provision across the NHS [9]. The blurring of the professional boundaries between nursing, medicine and other health care professions, which was already happening within specialities such as paediatric oncology, has now become government policy [8,10,11]. 'Making A Difference' set out the proposals for a new career framework for nurses linked in to proposals for a new pay scheme that was subsequently developed as part of 'Agenda for Change' [12]. This document set out government policy for the

establishment of nurse consultant posts, as one focus for the formulation of new clinical career pathways. It recognised some of the confusion and lack of consistency apparent in the proliferation of specialist nurses, and emphasised the need for all role development to be a ‘managed process’, designed primarily to benefit patients.

5. Key roles for nurses

The NHS plan gives further guidance as to government direction in promoting more flexible ways of working, and the continuing breakdown of the demarcations between staff groups [10]. The Chief Nursing officer’s ‘10 key roles for nurses’ set out in the plan gives further opportunities for nurses to develop their practice in a specialist role (Fig. 1). Developments around prescribing are particularly important for many aspects of care in paediatric oncology. The pathway to nurse prescribing is proving to be a long one, despite repeated statements of support from both government ministers and the Department of Health. Nurses have used Patient Group Directions to supply medication in clearly defined clinical situations [13], but there is a need for them to be able to extend this role into prescribing in situations where all members of the multidisciplinary team feel that this is appropriate. The limited numbers of conditions that can be addressed by independent nurse prescribers has meant that few nurses in paediatric oncology have yet taken on this role. The extended nurses’ formulary now being developed, and recent guidance on supplementary or dependent prescribing, however have greater potential for use in practice by expert nurses [14]. As palliative care is one of the areas specifically identified for development, a number of Paediatric Oncology Outreach Nurse Specialists are currently undergoing training as independent nurse prescribers. Supplementary prescribing, whereby nurses or other professionals, notably pharmacists, can pre-

scribe for patients once they have been assessed and diagnosed by a doctor, and a ‘clinical management plan’ established for their treatment, has obvious promise in a speciality which is distinguished by its use of multidisciplinary protocols for most aspects of clinical care. This is an area where further development can be confidently expected. There is a great deal of interest within many treatment centres in the establishment of nurse-led clinics and nurse-led care in chemotherapy [15]. The use of supplementary prescribing could help to move these initiatives forwards by making appropriate use of nurses’ knowledge. The prescription of anti-emetics according to an established protocol, and dose adjustments of continuation chemotherapy in the treatment of Acute Lymphoblastic Leukaemia are just two areas of possible development that could be addressed by this route. There are at present no specific education programmes for children’s nurses who wish to become nurse prescribers. The courses that do exist are directed primarily at the very different adult practice.

6. A framework for developing practice in paediatric oncology nursing

Within the speciality of paediatric oncology nursing since the 1990s there has been a recognised need to bring coherence and structure to the *ad hoc* development of nursing roles and a call for guidance in how to move nursing practice forward. The steering group of the Paediatric Oncology Nurses Forum of the Royal College of Nursing (RCN) were actively engaged with these issues, and convened a working party to take them forward. Developments in the speciality were reviewed in light of professional guidance, and government policy, and this resulted in the development of ‘a framework for developing practice in paediatric oncology nursing’ [16]. This framework is intended for use by nurses within the speciality to facilitate role development. It can be used by individuals looking to develop their own prac-

Chief Nursing Officer’s 10 key roles for nurses

- **To order diagnostic investigations** such as pathology tests and X-rays
- **To make and receive referrals direct**, say, to a therapist or a pain consultant
- **To admit and discharge patients** for specific conditions and within agreed protocols
- **To manage patient caseloads**, say for diabetes and rheumatology
- **To run clinics**, say for ophthalmology or dermatology
- **To prescribe medicines and treatments**
 - To carry out a wide range of resuscitation procedures including defibrillation
 - To perform minor surgery and outpatient procedures
 - To triage patients using the latest IT to the most appropriate health professional
 - To take a lead in the way local health services are organised and in the way that they are run

Fig. 1. Department of Health. The NHS Plan, London, DoH, 2000.

Table 1

Taken with permission from Gibson F, Soanes L. Long-term follow-up following childhood cancer: maximising the contribution from nursing. *Eur J Cancer* 2001, 37, 1863

Role	Clinical Nurse Specialist	Nurse practitioner	Consultant nurse
Purpose	<ul style="list-style-type: none"> • Provide collaborative and direct patient care • Provide patient and staff education and practice development • Provide information and consultancy services • Use nursing and medical diagnoses to plan care • Improve quality by direct care or through work with other nurses 	<ul style="list-style-type: none"> • Provide direct primary and speciality care in a number of settings • Provide full range of primary health-care services with a holistic patient and family focus • Use nursing diagnosis to plan care 	<ul style="list-style-type: none"> • Provide better outcomes for patients • Improve services and quality • 50% Clinical practice • Strengthen leadership • Provide a new career opportunity to retain experienced and expert nurses
Functions	<ul style="list-style-type: none"> • Expert practice • Education • Consultation • Research 	<ul style="list-style-type: none"> • Health promotion • Physical assessment • History taking • Establish medical diagnosis • Order, perform and interpret tests • Prescribe drugs • Refer patients • Provide emergency care 	<ul style="list-style-type: none"> • Expert practice • Professional leader • Consultancy role • Education, training and development function • Practice and service development • Research and evaluation function
Qualification and experience	<ul style="list-style-type: none"> • Educated to first or masters degree level • Specialist professional qualifications • Experienced and expert in a defined area of practice 	<ul style="list-style-type: none"> • Educated to first or masters degree level • Undertaken a nurse practitioner type programme • Specialist professional qualifications • Experienced and expert in a defined area of practice 	<ul style="list-style-type: none"> • Educated masters up to doctorate level • Considerable breadth and depth of clinical experience • Specialist professional qualifications considered appropriate for a 'higher level of practice'

tice, or by the whole multidisciplinary team looking at introducing new nursing roles to their particular service. Its use is recommended as it can help to ensure that the development of new roles is both a managed process and one which is focused on the needs of children, young people and their families [17].

There have been further attempts from within the speciality to bring greater clarity to the different roles that might be undertaken by the specialist nurse. A useful table developed by Gibson and Soanes [18] helps to define the different characteristics of the role of Clinical Nurse Specialist (CNS) Nurse Practitioner (NP) and Nurse Consultant as they have developed in the UK (Table 1). Some of these characteristics have arisen from role development in very different areas of practice, such as primary care. When used alongside the framework for developing practice [16,17] these characteristics can be used to describe roles currently in place, and plan towards future developments. This can only help in dispelling some of the confusion that persists in the disparate use of titles and the diverse nature of nursing roles across different services.

7. Current situation in the UK

When looking at defined nurse specialist roles there are three recognised titles that are most commonly used, the Clinical Nurse Specialist, the Nurse Practitioner or

Advanced Nurse Practitioner (the distinction between the two is unclear at present), and the Nurse Consultant. A survey of staffing levels in paediatric oncology units throughout the UK identified considerable variation in all aspects of service provision, including nurse specialist posts [19]. Some centres had introduced a number of posts, whilst others apparently had none. There was no obvious correlation between the size of the centre or the complexity of work undertaken to the number of specialist nurses in post.

Posts that carried the title of Clinical Nurse Specialist were often focused on a defined patient group; examples include Bone Marrow Transplant Clinical Nurse Specialists, Leukaemia or Haematology Nurse Specialists, and Nurse Specialists in Long Term Follow Up. Other roles focus upon a particular aspect of treatment and nursing practice, notably Chemotherapy Nurse Specialists, or Intravenous Therapy Nurse Specialists. The role undertaken by these nurses has not been well described, but is generally to lead practice in the care of that particular patient group, or aspect of clinical care. More work is needed to describe and evaluate such posts, and to look critically at the difference they make to patient care and practice development. Nurse-led clinics or other aspects of nurse-led care also need to be evaluated, and advances in practice disseminated more widely than is now the case.

A number of Nurse Practitioners and Advanced Nurse Practitioners are already in post. This is a role that has been best described in paediatric oncology at

the Alder Hey Hospital in Liverpool. [13]. The Nurse Practitioner has had a well-defined role in primary care, but the way such posts have been established in acute care is more variable. These are posts that in broad terms incorporate elements of medical decision making into autonomous nursing practice [20]. The role of the Advanced Nurse Practitioner in Liverpool, like earlier Clinical Nurse Specialist posts, was developed partly in response to perceived gaps in service provision, and in the context of changes to the training of junior doctors, as well as a perceived lack of development within the nursing team. The role carries a broader remit than a Clinical Nurse Specialist post and has been identified as encompassing: 'advanced autonomous clinical practice, independent research, education and case management with an emphasis on pioneering and innovative practice' [13]. The Advanced Nurse Practitioners in Liverpool see all children that attend the unit for 'routine' chemotherapy. They carry out a clinical assessment, which includes a full physical, social and emotional history on admission, highlighting new or ongoing problems. They oversee the management of each admission and ensure that follow up is well co-ordinated. Children who are admitted to the unit febrile and neutropenic may also be seen and assessed and their treatment initiated by the Advanced Nurse Practitioners. This is a role that has the potential for development across the speciality, and the current post holders recognise a need to evaluate the service they provide.

The role of the Paediatric Oncology Outreach Nurse has continued to develop, and is the most prevalent of the identified specialist roles seen in the majority of treatment centres. Post-holders carry defined patient caseloads and individuals have developed their role in many aspects of expert symptom management, particularly in the practice of palliative care. There is considerable variation in the way these nurses work, and this is affected by the geographical location of the regional centre, and the patient population that it serves. The different levels of support offered by local primary health care teams, and the availability of children's community nursing teams, will also have an impact on the role of the outreach nurse. The only established Nurse Consultant post in paediatric oncology in the UK has been developed in the context of an outreach nursing service, the Nurse Consultant in Oncology Outreach and Palliative Care at the Alder Hey Children's Hospital in Liverpool. This is a relatively new post and as such evaluation is planned.

8. Clinical care

Children and young people with cancer require complex care, delivered across different clinical settings along the course of their treatment. Nurse specialist

and nurse practitioner posts will always include a large clinical component in their work, but it must be recognised that they are, and always should be, additional to the nursing establishment needed to deliver care at the bedside, or in the clinic [9]. All nurses working in the speciality of paediatric oncology require well-developed nursing skills, which encompass both paediatric nursing expertise and specialist oncology skills and knowledge in order to deliver the care needed by the child and family. This is a complex and challenging speciality [21] and makes considerable demands on the nurses who deliver 'front-line' care. Nursing must be developed and supported across the breadth of the workforce, and too great an emphasis on the development of specialist posts risks detracting from the availability of appropriate levels of expertise throughout the nursing team [20].

In a study evaluating educational preparation for children's cancer nurses [22], both an expert panel and a panel of service users (children, young people and their families) were quite clear about what was required from nurses working in the speciality. Essential qualities included the ability to work in partnership with children and families, particular clinical skills, multidisciplinary working, and an array of identifiable personal attributes. The required clinical skills that were identified included the management of central lines, drug administration, and symptom management. These essential attributes and skills were felt to be required from all nurses working in the speciality. Interestingly, it was much more difficult to elicit from the panels additional descriptors of a different level of 'expert' practice of the kind that might be thought to be required in a defined 'nurse specialist' role.

Many nurses working in paediatric oncology practice beyond traditional nursing boundaries, for example in the delivery and management of cytotoxic drug treatment regimes and complex intravenous therapy. Their assessment skills must be developed to manage vulnerable, sick and unstable children. The supportive role of nurses, which demands strong interpersonal skills, is well recognised. Paediatric oncology is a challenging speciality, and many services are struggling to maintain the nursing establishments they need to provide safe and effective care [19]. It is essential that ways are found to recognise the significant responsibilities that individual nurses take on, which are very different from the demands made on nurses working in other areas. Due to the complexity of care required for children and young people with cancer, it is essential that there is clear clinical leadership on in-patient wards and in day care and clinic settings. Nurses who have well-developed specialist skills, knowledge and expertise, but may not be identified by the title of 'nurse specialist' must provide the leadership which is critical at the point at which care is delivered.

9. Educational preparation

In developing the skills needed to work in such a demanding speciality education and training are clearly fundamental. The demise of the English National Board (ENB) for nursing, and the definitive move of nursing education into the universities have contributed to the recognised lack of a defined pathway of specialist educational preparation for children's cancer nurses in the United Kingdom [23]. Educational and career pathways in the speciality are as diverse as the individuals who follow them. Post-registration education for nurses currently encompasses diploma, degree or masters level courses. The loss within the UK of the ENB 240 course on the 'Care of the Child with Cancer' removed a stable benchmark of specialist education from within the speciality [22]. There is little agreement nationally on the agreed clinical outcomes for nurses completing post-registration courses in specialist practice [24]. The Paediatric Oncology Nurse Education group has worked as a body to try and maintain consistency in educational preparation across the speciality. Those wishing to undertake specialist education at degree level currently have a limited number of options, with a degree in either child health or in cancer, at one of those few institutions which now provide specific modules or programmes which address the care of children and young people with cancer. There is, however, a new national framework for a degree in Children's Cancer Nursing under development, with funding from Macmillan Cancer Relief, and support from the Paediatric Oncology Nurse Education group, which will be available as a distance learning course.

Masters level education and preparation is perhaps inevitably undertaken on a very individual basis. This is a small speciality, and the number of individuals wishing to study at this level will be small in any one educational institution. Such preparation will often be very much a 'do it yourself' operation, with access to Masters level preparation that is the 'best fit' to the role being developed, or the individual's needs. There are an increasing number of Masters courses and 'student designed' awards which focus on independent clinical practice, embedded in the individual's work place and role, that can provide appropriate preparation for a role centred on advanced and autonomous clinical practice. In Scotland, nurses looking to develop their role can work towards the qualification of Specialist Practitioner.

Education is critical to the continuing development of the speciality, and it is vital that nurse specialists from within children's cancer nursing take the opportunity to guide the commissioning of education and the development of a skilled workforce [11].

10. Research and development

There are now a number of individuals who have studied up to PhD level, and whose independent research has contributed substantially to the body of nursing research in paediatric oncology. Post-graduate studies need to be encouraged in order for cancer nursing for children and young people to gain increased credibility as a speciality. Whilst there has been some research looking at the potential for role development in paediatric oncology, it has been limited in its scope. One limiting factor is the identification of meaningful outcome measures for nursing interventions and their impact on patient care [25].

Nurses are taking on new roles in developing care, and there is considerable interest in the development of initiatives such as nurse-led clinics [18]. Research has been undertaken to evaluate the potential for such initiatives at a local level [20] and in a small speciality like paediatric oncology there is enormous potential to learn from the work of others. Further work is needed to evaluate the contribution that specialist nursing can make to clinical care as it is only through audit and research that such innovations in practice can lead to real and reproducible improvements across the speciality.

11. Conclusions

The need for specialist nursing care for children and young people with cancer has been recognised and supported in a series of reports from both within and outside the speciality [26–28]. This care is given at the bedside, in the day care unit, and in the patient's home, by nurses with a wide range of knowledge and expertise. It can be argued that the development of defined 'specialist nurse' posts has the potential to detract from the provision of appropriate nursing care where it is perhaps most needed, as the proliferation of such posts may, in theory at least, dilute the body of skills and experience at the point of care. The temptation to plug gaps in service provision by the creation of a nurse specialist can result in a more fragmented service and a reduction in professional development across the nursing team. On the other hand, such posts have the real potential to stream-line services, and offer a better experience for patients and families [13]. There is a need to examine consistency in specialist role development, and to evaluate more effectively those posts which are already in existence. The role of the specialist nurse in all its different manifestations is to provide effective leadership in shaping the delivery of nursing care. These roles must therefore be focused on the monitoring and improving of standards of care and the provision of skilled nursing leadership across the key domains of nursing endeavour. Nurses with specialist knowledge, skills and expertise are needed in positions

where they are able to develop nursing practice, direct service development, lead nursing research, and guide education and training.

Conflict of interest statement

None declared.

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