Mixed Funding Within the British Health Care System: An
Examination of the Effects on Professional Relationships Between
Paediatric Oncology Outreach Nurse Specialists and Other
Health Care Professionals

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Abstract

Stemming from the White Paper *Working for Patients* (DoH 1989a), the National Health Service (NHS) has undergone major reform over the last decade. Central to this process has been the ethos of a market driven economy, with increasing reliance on ‘income-generating’ schemes. Voluntary sector funding has been particularly called upon to assist with establishing ‘new’ nursing services, which are commonly clinical nurse specialist posts. A particularly successful example has been found in the naissance of the Paediatric Oncology Outreach Nurse Specialist (POONS). In order to improve the services offered to children with cancer and their families, bereaved families have been actively involved in raising funds to establish charities to fund POONS posts. The ways in which charities have been established have largely resulted from the personal experiences of families wishing to improve on the services they received during their child’s care and terminal illness. As a result of this, personal agendas have influenced the strategies of the charities concerned. However, the ways in which these strategies impinge on POONSs and those who they work with has, to date, not been examined.

This research explores how the strategies adopted by key charities funding POONSs influence their working practices and the structure and organisation of their services. A second aim is to examine whether, in turn, the relationships between POONSs and other health care professionals with whom they work, are affected by the strategies adopted by different charities who provide funds for POONS services.

Empirical data were collected from all POONSs throughout the United Kingdom and the Republic of Ireland. Forty three POONSs were interviewed either by telephone or in person. Two ‘Funder’ models were identified, reflecting the divergent strategies of the two main charities funding POONS posts: the Cancer Relief Macmillan Fund (Macmillan model) and Cancer and Leukaemia in Childhood (CLIC model). A third model was associated with funding from smaller professionally-directed charities and the NHS. These models were built upon in undertaking case studies at three locations, during which a diverse group of health care professionals were interviewed. In all 65 focused interviews were held transcending community and acute hospital sectors.
POONSs associated with the Macmillan model were identified with having a hands-off approach to nursing and worked at regional children's cancer treatment centres. Those affiliated to the CLIC model provided hands-on care to children at district general hospitals (DGHs). Those identified with a 'Mixed Funders' model displayed elements of the other two models, adopting a mixed hands-on and hands-off technique and working at both regional centres and DGHs.

Two professional relationship typologies have been developed: one that exists between POONSs and primary health care teams, and a second between POONSs and hospital-based health care professionals. The former typology comprised three types of relationship: 'Empowerment' associated with hands-off care; 'Disempowerment' associated with hands-on care and 'Partnership' identified with both hands-on and hands-off nursing care. Four types of 'partnership' were evident in a second typology: 'Relinquishment' where POONSs at DGHs provide hands-on care to children in hospital, handing over the care to ward staff only in their absence; 'Hierarchical Ascendancy' where consultants at DGHs control the work of POONSs; 'Integrated Reciprocity' where regional POONSs and hospital colleagues share the care of children, mindful of each others' roles; and 'Independent Reciprocity' when regional POONSs share the care of children with other hospital-based staff, sometimes obliviously.

In general, the ways in which POONSs' services are structured, organised and delivered, the degrees of knowledge achieved by them and the relationships formed between POONSs and other health care professionals are significantly affected by the nature of funders within the current mixed economy of health care. The nature of funding has implications for the professionalization of nursing, for the theoretical construction of interprofessional relationships, and for future policy directions within the NHS.
This thesis is dedicated to those many families that I have known and supported through the deaths of their children without whose plight and in whose interest, this study would not have been inspired. In particular it is dedicated to Paul and his mother Olive who inspired me to become a community nurse which assisted in the naissance of the nursing specialty which has become known as 'POONS'.
Any names that appear in this text are fictitious to maintain anonymity
The Little Girl Lost

I
In futurity,
I prophetic see,
That the earth from sleep
(Grave the sentence deep)

III
In the southern clime,
Where the summer's prime
Never fades away,
Lovely Lyca lay.

V
'Sweet sleep, come to me
Underneath this tree;
Do father, mother weep?
Where can Lyca sleep?

VII
'If her heart does ache,
Then let Lyca wake;
If my mother sleep
Lyca shall not weep.

II
Shall arise, and seek
For her Maker meek;
And the desert wild
Become a garden mild.

IV
Seven summers old
Lovely Lyca told.
She had wandered long,
Hearing wild bird's song.

VI
'Lost in desert wild
Is your little child.
How can Lyca sleep
If her mother weep?

VIII
'Frowning, frowning night
O'er this desert bright
Let thy moon arise,
While I close my eyes.'

IX
Sleeping Lyca lay
While the beasts of prey,
Come from caverns deep,
View'd the maid asleep.

William Blake (1757-1827)
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And last, but certainly by no means least, I would like to express my eternal gratitude to members of my family, friends and colleagues with whom I have been particularly difficult during the period in which I wrote up this thesis!
List of Abbreviations

ACT  Association for Children with life-threatening or Terminal conditions and their families
ALL  Acute Lymphoblastic Leukaemia
ANP  Advanced Nurse Practitioner
BMT  Bone Marrow Transplant
CLIC Cancer and Leukaemia in Childhood
CNM  Clinical Nurse Manager
CNS  Clinical Nurse Specialist
CRMF  Cancer Relief Macmillan Fund
CVAD  Central Venous Access Device
DHSS  Department of Health and Social Security
DGH  District General Hospital
DN   District Nurse
DoH  Department of Health
EN   Enrolled Nurse
ENB  English National Board
GOS  Pre 1993 The Hospitals for Sick Children, Great Ormond Street Post 1993 Great Ormond Street Hospital for Children NHS Trust
GP   General Practitioner
HV   Health Visitor
ITU  Intensive Care Unit
LATCH  Llandough Aims to Treat Children with Cancer and Leukaemia with Hope
Mac  Macmillan
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<td>MCR</td>
<td>Macmillan Cancer Relief</td>
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<td>M.F.</td>
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<td>MPN</td>
<td>Macmillan Paediatric Nurse</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
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<td>NHSME</td>
<td>National Health Service Management Executive</td>
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<tr>
<td>NNP</td>
<td>Night Nurse Practitioner</td>
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<td>OPD</td>
<td>Out-Patient Department</td>
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<td>PCN</td>
<td>Paediatric Community Nurse</td>
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<tr>
<td>PHC</td>
<td>Primary Health Care</td>
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<td>PHCT</td>
<td>Primary Health Care Team</td>
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<td>PMN</td>
<td>Paediatric Macmillan Nurse</td>
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<td>POCNS</td>
<td>Paediatric Oncology Community Nurse Specialist</td>
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<td>POONS</td>
<td>Paediatric Oncology Outreach Nurse Specialist</td>
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<td>POCNSIG</td>
<td>Paediatric Oncology Community Nurses Special Interest Group</td>
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<tr>
<td>POONSIG</td>
<td>Paediatric Oncology Outreach Nurses Special Interest Group</td>
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<tr>
<td>PONF</td>
<td>Paediatric Oncology Nurse Forum</td>
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<tr>
<td>RCN</td>
<td>Royal College of Nursing</td>
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<td>RGN</td>
<td>Registered General Nurse</td>
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<tr>
<td>RHA</td>
<td>Regional Health Authority</td>
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<tr>
<td>RN(Child)</td>
<td>Registered Nurse - Child Branch</td>
</tr>
<tr>
<td>ROS</td>
<td>Removal of Sutures</td>
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<tr>
<td>RSCN</td>
<td>Registered Sick Children’s Nurse</td>
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<td>SCT</td>
<td>Symptom Care Team</td>
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<td>SHO</td>
<td>Senior House Officer</td>
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<td>SN</td>
<td>Staff Nurse</td>
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<tr>
<td>Sr</td>
<td>Sister</td>
</tr>
<tr>
<td>SR</td>
<td>Senior Registrar</td>
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<tr>
<td>SW</td>
<td>Social Worker</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>UKCC</td>
<td>United Kingdom Central Council for Nursing, Midwifery and Health Visiting</td>
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<tr>
<td>UKCCSG</td>
<td>United Kingdom Children’s Cancer Study Group</td>
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<td>USA</td>
<td>United States of America</td>
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PART ONE - THE INTRODUCTION
Chapter One - Introduction

Background to the Study
The foundations for this research were laid down more than a decade before its proposal when, as a sister working at a regional children's cancer treatment centre, I watched frustratingly, a close colleague struggling to establish one of the earliest specialist outreach nursing services caring for children with malignant disease in the United Kingdom (UK). The following account encapsulates many of the issues that this research is seeking to explore.

Katrina was an experienced health visitor, also trained in cancer nursing and had worked as a sister on the same children's cancer unit as myself; she was hard working and dedicated to her cause of establishing good home care services and support for children with cancer and their families. She was also concerned about forging good communication networks between the specialist centre where we both worked and primary health care teams (PHCT) involved in sharing care, most particularly during childrens' terminal illnesses. Perhaps her only downfall in attempting to 'pioneer' a 'new' nursing service was her quiet, reassuring manner, not typical of clinical nurse specialist (CNS) personality types (see Chapter Two).

Although one of the consultant paediatric oncologists was very supportive of her cause and rôle, during the time that Katrina and I worked together she had a constant struggle to maintain funding in order to take on an additional colleague and continue running her service. More especially she battled with senior nurse managers, more experienced in managing adult nursing services, regarding funds for travel expenditure and differences in perceptions about the role. Much of her funding was originally provided through a mixture of charitable and exchequer sources. Today, fourteen years later, the team which she fought so hard to establish has only recently blossomed, now comprising three paediatric oncology outreach nurse specialists (POONs) with a stable source of income. Funding and a difference in perceptions regarding this specialist nursing post have, until recently, remained contentious issues.
It was with inspiration from Katrina that twelve years ago I found myself in the fortunate position of being able to set up a new paediatric oncology outreach nurse specialist (POONS) service at an additional London-based regional children's cancer treatment centre. The difference for me was that funding seemed to be in abundance to instantly establish a team of four members including our own secretary and senior registrar (SR). Our service flourished and within two years we were able to expand our team to include a third nurse specialist, whilst some time later the SR became the first doctor to be appointed as a consultant in paediatric palliative care.

Four years into our service however, disaster struck: the charitable organisation which had funded us from the outset went bust overnight - we were without funding. Fortunately for the team and the families who we served, within one week an alternative charity had offered to take over our costs, which they did until funding was found from within the hospital budget to take the team on as fully paid members of the National Health Service (NHS).

During the six and a half years that I worked as a CNS with the Symptom Care Team (SCT) I watched and assisted in the setting up and development of other POONS services throughout the UK and the Republic of Ireland. This observation and participation was not carried out however, without many frustrations, noting the lack of thought and preparation which often appeared to go hand-in-hand with establishing POONS posts. Frustrations became particularly exacerbated when charitable funding appeared to be offered to reduce the financial burdens from exchequer (and more recently, NHS Trust) funds, all too eagerly taken up by managers with little thought given for future financing of POONS services. As a result of my involvement in supporting other POONSs, particularly those employed to work on their own, I instituted a support network through the Society of Paediatric Nursing of the Royal College of Nursing (RCN) to which all nurse specialists in the field were invited (this group later became known as the Paediatric Oncology Community Nurses Special Interest Group and later still developed into the Paediatric Oncology Outreach Nurses Special Interest Group). Today this network is going strong, has recently developed regional subgroups and become incorporated into the Paediatric Oncology Nurses...
Forum (PONF) of the RCN. From within this group close friendships have developed which are much valued today.

From this group many issues of common concern arose. Not least were concerns regarding issues of funding for the establishment of POONS posts: who supplied the funds, how funding was provided, the influences of certain charities on how services were established and how POONSs funded by different charities often had differing working patterns. These issues were also shared with senior medical staff (more usually consultants) working with POONSs who were frequently responsible for initiating funds for such services, and by several Sargent social workers\(^1\) whose rôles, in part, closely reflected those of POONSs. As a consequence of this mutual concern, and perhaps unusually, funding to conduct the work which has contributed towards my doctoral studies was successfully gained through a joint nursing and medical initiative. Funding was obtained through the Department of Health (DoH) Initiative: ‘Pilot Projects for Children with Terminal and Life Threatening Illnesses’ (DoH 1998), a joint steering group was subsequently established and the project: ‘POONS\(^2\): Towards a Model of Good Practice’ was conceived. The intention of the steering group was to examine the effects of different funding organisations upon the work of POONSs and to recommend a ‘best practice’ model. The collaboration between medicine and nursing, and the relationship between POONSs and medical staff with whom they work so closely, underpins a number of the important themes developed in this thesis and the work which contributed towards the DoH project (Hunt 1996, DoH 1998) placed no constraints on the methodology.

\(^1\) Until recently referred to as Malcolm Sargent Social Workers and funded by the charity: Malcolm Sargent Cancer Fund for Children, these are specialist social workers based in hospitals to work as part of the multi-disciplinary team caring for children with malignant disease and their families. More usually located at regional childrens’ cancer centres, some are also situated within paediatric departments at larger district general hospitals (DGH).

\(^2\) POONSs were originally known as ‘community’ nurse specialists, rather than ‘outreach’ nurse specialists.
Issues of funding sources of POONSs have also been of interest to one of the charities associated with financing their work: the Cancer Relief Macmillan Fund (CRMF). Through concern to acknowledge 'their' POONSs, CRMF, in conjunction with the DoH, commissioned a parallel study to be undertaken by a research team at King's College, London. This qualitative study (Bignold et al. 1994a, 1994b, 1995a, 1995b, Cribb et al. 1994) particularly focused on the work of Macmillan Paediatric Nurses (MPN) and adopted a case study approach at a hospital where POONSs were funded by CRMF. In recognition of this work, and of a need to obtain a more global and quantitative approach, the research study highlighted in this thesis was designed to complement the work of Bignold et al. (1994a, 1994b, 1995a, 1995b) and Cribb et al. (1994).

**Aim of the Study**

The study of the working practices of POONSs and their professional relationships arose though a concern regarding their mixed funding sources. POONSs provide a good example of health care professionals to examine the effects of non-statutory funding on their services, since most have, at some time, been funded by charities. The increasing reliance upon voluntary and private sector funding within the British health care system (discussed in Chapter Three), makes this an important area for study. However POONSs may also be regarded as a unique group, making this a critical case study. The highly emotive nature of childhood cancer attracts much public attention. This means that voluntary contributions are collected with relative ease for any component of a child's care, be it medical or social. Hence POONS posts have been established with little difficulty, when compared to health care professionals working in other specialties. Charitable funding has assisted with the growth from a few isolated POONS posts at a small number of hospitals, into a specialist group of nationally recognized CNSs within the field of paediatric oncology. The rapid establishment of this small nursing specialty, with recognition enhanced through the Paediatric Oncology Community Nurses Special Interest Group

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3 CRMF have more recently become known as Macmillan Cancer Relief (MCR). However during the course of this study the charity was known as CRMF. The charity is therefore referred to as CRMF throughout this thesis.
(POCNSIG) (later referred to as the Paediatric Oncology Outreach Nurses Special Interest Group (POONSIG)), have given a uniqueness to POONSs unequalled by other sectors of health care. Both their uniqueness and their representativeness in the changing balance between private/voluntary and public sector funding have made POONSs a good group of health care professionals to study.

This research acknowledges that throughout history, without the voluntary sector, advances in health care might have been hindered (for example the efforts of Marie Stopes to implement birth control). Without the support of voluntary sector funding it is questionable whether the services of POONSs would have been so successfully developed. Nevertheless there are problems which arise from reliance upon voluntary sector funding. Some of these problems, in relation to POONSs, have given rise to this research.

The main questions to be addressed in this thesis are:

(1) How do mixed funding sources affect the clinical practices, organisation and structure of services provided by POONSs?

(2) How do the mixed funding sources of POONSs affect the professional relationships between POONSs and other health care professionals.

(3) How does the mixed economy of health care affect the degrees to which POONSs become 'specialists' and do perceptions of 'specialist knowledge' affect the ways in which professional relationships between POONSs and others are constructed?

(4) Do mixed funding sources affect the ability of POONSs to function as an homogenous group thereby affecting the 'professional project' of nursing? If so what are the prohibiting and/or unifying factors?
Outline of the Thesis

This thesis is structured in three parts. The first part introduces the issues mapped out in the research through reviewing sociological, nursing and medical literature. Chapter Two begins with an overview of the management of childhood malignancy; in drawing extensively on medical and nursing literature, it suggests that the rarity of malignant disease in childhood requires a complex system of care across three settings: primary, in which care may be provided by PHCTs including the general practitioner (GP), the health visitor (HV), the district nurse (DN), the paediatric community nurse (PCN⁴), practice nurse, school nurse or any combination of these health care professionals; secondary, in which children may be cared for at the local hospital; and tertiary where care is provided at specialist centres. This complex system of care, it is argued, may lead to anxieties both for families and health care professionals caring for them, particularly those inexperienced in working with such families. In this chapter I suggest that the combination of parental anxieties and the nature of care provision were, in part, responsible for the emergence of the group of specialist nurses who are the subject of this study, namely POONSs. The second part of the chapter outlines the position of POONSs within the context of current community-focused policies, whilst the latter part of the chapter reflects more generally upon the development of specialist nursing rôles. Whilst this thesis focuses on issues pertaining to POONSs, in this second chapter it is argued that, funding aside, the complexity and lack of clarity concerning CNS roles have been and continue to present problems. These include a lack of distinction between the CNS and the Advanced Nurse Practitioner (ANP) rôle and their educational requirements.

Chapter Three contextually places the mixed funding sources of POONSs within the broader setting of health service financing. A focused review of the literature explores the rationale for the establishment of the NHS, through examining the development of health services for sick children and community nursing. In this chapter I suggest that problematic issues of mixed (i.e. charitable) funding sources contributed towards

⁴ PCNs have more recently become known as childrens' community nurses (CCN). However the term PCN is adopted throughout this thesis since it was in common use when the fieldwork for this study was undertaken.
the initiation of the NHS. Inspite of these issues, the establishment of POONS posts through charitable sources, may be seen as an example of a wider return to greater dependence upon private and voluntary sector funding. Also within Chapter Three the strategies of the different charities associated with funding POONS posts are reviewed, suggesting that the two main charities: CLIC (Cancer and Leukaemia in Childhood) and CRMF, adopt divergent approaches. In particular it is suggested that these differing strategies determine whether POONSs work at regional childrens’ cancer centres or within paediatric departments at district general hospitals (DGHs).

Chapter Four concerns professional relationships between health care professionals. It draws upon both sociology of the professions and nursing literature to examine the significance of education and experience in the acquisition of ‘specialist knowledge’. Here I argue that although education and experience are both perceived to contribute towards becoming ‘expert’ through the nursing literature, the place of experience and intraprofessional specialisation in relation to professionalization, has been overlooked in the sociology literature. Since the focus of this research has been to examine the relationships between POONSs and other health care professionals with whom they closely work, the second part of the chapter reviews the literature on relationships between doctors and nurses and between nursing groups themselves. Here I suggest, firstly, that whilst the relationships between doctors and nurses have significantly altered during the last thirty years, elements of patriarchy still exist in some situations. Secondly, relationships between nurses themselves are examined to suggest that little is understood about the dynamics of relationships amongst groups of nurses. However it will be argued that relationships with CNSs are varied and influenced in particular, by the nursing specialty and the degree of hands-on nursing care provided to patients by CNSs, in the community.

The final section of the chapter continues the theme of professional relationships by examining the notions of ‘empowerment’ and ‘partnership’. I contend that whilst both concepts currently hold much favour politically and professionally, little research has investigated these concepts in relation to the working relationships between health care professionals. Whilst there is much rhetoric about professionals empowering
others and working "in partnership", in reality these concepts have primarily focused on relationships between health care professionals and their clients/patients.

The second part of this thesis concerns the research. Chapter Five primarily outlines the quantitative research methodology, highlighting a survey undertaken with POONSs. However, it does set the methodological framework for both this phase of the research and the second, qualitative stage. Chapter Six describes the influences of mixed funding sources upon the work, structure and organisation of POONSs. It suggests that the opposing strategies of CLIC and CRMF significantly affect how POONS services operate and describes the three 'Funder' models which emerged from analysis of the survey. It also sets the scene for the second stage of the research.

Chapter Seven discusses the qualitative methods adopted to gain perspectives on working relationships between POONSs and those who they work with, and gives details of three case studies. It is primarily descriptive, detailing the hospital locations at which this work was undertaken. Chapters Eight and Nine draw on this data to set the scene for the following conceptual chapters. Common issues arising for health care professionals across community settings, from the case study data are described in Chapter Eight whilst matters common to hospital-based health care professionals are discussed in Chapter Nine.

The tenth chapter discusses the degrees to which POONSs attain 'specialist' status by focusing on the concept of 'specialist' knowledge. Here I argue that whilst funding sources significantly influence the level of knowledge of POONSs both in terms of their professional training and their past experiences, 'specialist' status is conferred on all POONSs by the health care professionals they work with. It is dependent upon health care professionals' own experiences of in this case, childhood cancer. In other words I suggest that 'specialist' pertains to someone with greater knowledge than oneself. In addition to 'specialist knowledge', the significance of personality is also highlighted.
Chapter Eleven centres on professional relationships between POONSs and PHCTs whilst the focus to Chapter Twelve is on relationships with hospital-based colleagues. The concepts of ‘partnership’ and ‘empowerment’ are employed in Chapter Eleven to suggest that funding sources of POONSs affect the types and degrees of professional relationships achieved between POONSs and PHCTs. Similarly the notion of ‘partnership’ is used in Chapter Twelve to suggest that the concept is employed in a variety of ways to construct relationships between POONSs and hospital-based colleagues. It is argued that the types of ‘partnership’ which emerge are strongly influenced by the degrees to which POONSs are perceived to have acquired specialist knowledge and consequently the extent to which they have accomplished ‘ownership’ of patients and their families and ‘leadership’ during terminal care.

The final chapter in the thesis draws conclusions from this study. Here I suggest that there are both policy and theoretical implications. I assert that new light has been shed on the relationships both between nurses and doctors and between groups of nurses. In particular, I will contend that whilst some specialist nurses work within patriarchal relationships with doctors, others are highly specialised and have acquired greater ‘medical’ expertise than doctors. Here they attain a more knowledgeable and therefore more powerful position than senior doctors. This is manifested by assuming overall responsibility for patients’ medical care. I also suggest that the contribution of intraprofessional specialisation and experience have been significantly undervalued in sociological discussions on the professions. Furthermore this chapter will suggest that the service provision of POONSs is fragmented and cohesion amongst this group of specialist nurses, whilst apparent at one level, is prevented by the strategies of their funding organisations. These divergent strategies undermine nursing’s current drive towards professionalization.
Chapter Two - Setting the Scene

Introduction
This empirical study has been based on a group of recently emerged CNSs, who have become known as Paediatric Oncology Outreach Nurse Specialists (POONSs). The aim of this chapter is to set the context of this study highlighting reasons behind the origins of the nursing specialty. The scene for the research will therefore be set from four dimensions; firstly this chapter discusses childhood cancer, focusing on the epidemiology and the management of its treatment and care. In so doing, it locates the origins and the ethos of POONSs and highlights the emotional stresses, for health care professionals, of caring for a dying child; thirdly the development of POONSs is grounded within the general evolution of the CNS rôle and fourthly the development of POONS roles is established within the context of current policies pertaining to sick children.

Malignant Disease in Childhood
Malignant disease in childhood comprise of both cancers (malignant growths in body tissues) and leukaemia (proliferation of abnormal blood cells) and differs greatly from malignant diseases associated with adults. The most common forms of childhood malignancy are acute lymphoblastic leukaemia (ALL) and brain tumours although many other rarer tumours exist. Malignancy in childhood is rare: in Britain about one in 10,000 children under the age of sixteen years are diagnosed each year (Draper et al. 1982, Pinkerton 1993, Foot 1995). This means that approximately one in 600 children develop cancer during the first 15 years of life (Morris-Jones & Craft 1990, Botting 1995). Since the introduction of radiotherapy treatment to prevent the spread of malignant leukaemia cells from the bone marrow and circulatory system to the brain during the early 1970s, and the introduction of multiple drug therapies, the long term outlook for childhood malignancies has rapidly improved. The five year survival rate for children with ALL has risen from 20% during 1968-1970 to just over 50% for 1977-1979 (Eden at al.1988); today the figure exceeds 75% (Childhood ALL Collaborative Group 1996). The five year survival rate for all forms of childhood malignancy is currently about 70% (Botting 1995, Banner et al. 1996) and it has been
estimated that by the year 2000 one in 1,000 of all young adults in both the UK and the United States of America (USA) will be long term survivors of childhood cancer (Morris-Jones & Craft 1990, Overbaugh & Sawin 1992, Wallace 1994). This has given rise to the increasing interest in the physical, psychological and social problems encountered by long-term survivors of childhood malignancy (for example see Li et al. 1987, Morris-Jones & Craft 1990, Chang 1991, Overbaugh & Sawin 1992, Pinkerton 1992, Rodgers et al. 1992, Wallace 1994, Banner et al. 1996, Bignold et al. 1996, Eiser et al. 1996) and to a newly emerged subspecialty within paediatric oncology. Inspite of today's successes however, one third of all children with malignant disease will die. This accounts for one in five of all childhood deaths between the ages of one and fourteen (Botting 1995) and is one of the commonest causes of death in childhood (Baum 1994).

The rarity of such a disease means that a paediatric department within any given district health authority in Great Britain will be referred a mean of 2.7 new referrals each year¹, caring for even fewer terminally ill children. It has been estimated that a GP will see only one or two children with a malignant disease throughout the duration of his or her career (Pinkerton 1993). The rarity of this disease has meant that since the 1960s there has been an increasing tendency to centralise care in order to improve treatment and reduce long-term morbidity and mortality rates. The importance of the centralisation of cancer care not only for children but also for adults, has recently been recognised through two government initiatives; firstly through the Lilleyman Report (CSAG 1993) which reviewed the positive effects of the centralisation of treatment for childhood leukaemia and secondly the Calman-Hine Report (DoH 1995a) which arose through the variance in levels of cancer care and mortality rates of adults, reported throughout the UK.

¹ These data were prepared with the kind assistance of Charles Stiller of the UKCCSG for the sole purpose of this study. Referrals to regional centres by local hospitals were examined between 1989-1992. Numbers of children diagnosed with malignant disease annually are constant, neither increasing nor decreasing.
A consequence of the centralisation of care for children was to formulate the United Kingdom Children’s Cancer Study Group (UKCCSG) in 1977, to which all paediatric oncologists currently belong (Stiller 1988, 1989). Today there are 22 established and recognised regional childrens’ cancer centres throughout the UK situated in major hospitals, located in large towns or cities within each regional health authority\(^2\) (Figure 2.1). Centres differ in size by the numbers of children referred each year and range from approximately 25-170 new patients annually (UKCCSG 1993, 1995). Whilst some smaller centres function within general paediatric ward environments, larger centres are housed within their own specialised units. Nonetheless all UKCCSG centres are staffed by medical, nursing, social work and affiliated health care professionals trained and/or experienced in paediatric oncology. The UKCCSG are closely linked to PONF of the RCN with whom conferences are jointly organised and working parties commonly established.

From the UKCCSG treatment trials are formulated, which have led to improved long term survival and reduced morbidity for many children. It is now widely acknowledged that the diagnosis, treatment, early monitoring, management and supervision of childhood malignancy is best achieved through the early referral of children to regional childrens’ cancer treatment centres to which the majority of children are referred (Eden et al. 1988, Stiller 1988 1989, Pritchard et al. 1989, Stiller & Draper 1989, Morris-Jones & Craft 1990, Pinkerton 1993, Wallace 1994).

**Sharing Care**

The direction of treatment and care by regional UKCCSG centres often involves a complex system of care which may be shared between primary, secondary and tertiary health care professionals (Muir et al. 1992). This arrangement in health care is increasingly common and is referred to as ‘shared care’ (e.g. Bacon 1989, Bennett et al. 1994, Orton 1994, Hooker & Williams 1996); it often results in some children being treated many miles from home. Degrees of ‘shared care’ vary depending on the

\(^2\) Regional health authority (RHA) is defined here as that which existed prior to the abolition of the RHA during the review of NHS management (NHSME 1993a).
UKCCSG Centres (22)

(1) Aberdeen
(2) Belfast
(3) Birmingham
(4) Bristol
(5) Cambridge
(6) Dublin
(7) Edinburgh
(8) Cardiff
(9) Glasgow
(10) Leeds
(11) Leicester

(12) Liverpool
(13) Great Ormond Stree
(14) St Bartholomew's
(15) Manchester
(16) Newcastle
(17) Nottingham
(18) Sheffield
(19) Southampton
(20) Royal Marsden
(21) Middlesex
(22) Oxford
type of malignant disease and subsequent treatment regime required by individual children and the stage a child has reached along his or her ‘cancer journey’. However it also differs between centres. Some UKCCSG centres practice minimal levels of shared care between themselves and the referring DGH, with paediatric oncologists preferring children to be admitted to the regional centre for each hospital admission, regardless of the reason for the admission. Other centres have well established ‘shared care’ with local referring hospitals. In one region where several UKCCSG centres exist and where shared care has been practised to varying degrees for some years, criteria has recently been established whereby the administration of anti-biotics and blood products (often required to correct the side effects of treatment) and the management of some chemotherapy is taken over by the local hospital under the direction of the regional centre with whom ‘shared care’ is practised (South Thames Paediatric Oncology Working Party 1996). This criteria is dependent upon the levels of paediatric experience of both nursing and medical staff and acknowledges that not all local hospitals achieve the directives of The Patient’s Charter: Services for Children and Young People Act (DoH 1996a). The Charter makes recommendations concerning the staffing levels of children’s wards in general hospitals. It states that a minimum of two qualified children’s nurses should be on duty at any one time; such recommendations during a shortage of Registered Sick Childrens’ Nurses (RSCN) or Registered Nurses (RN) (Child) are idealistic and remain unfulfilled in some childrens’ wards. Nurses working in DGHs with oncology nurse training are therefore an added bonus and not a prerequisite of the South Thames Paediatric Oncology Working Party criteria for ‘shared care’.

The concept of ‘shared care’ may also be applied when the emphasis of care switches from being hospital-based to community-based (Bennett et al. 1994, Orton 1994). Home is usually the place of preference for families when a child becomes terminally ill (Kohler & Radford 1985, Martinson et al. 1986, Chambers et al. 1989). ‘Shared care’ may therefore exist between PHCTs and tertiary centres, between PHCTs and secondary care with the local paediatric team or between primary, secondary and tertiary health services, with emphasis placed upon primary care.
Although there are benefits to families of sharing care between the local community and the regional centre, which include reduced cost and time spent travelling (Lansdown & Goldman 1988, Bacon 1989) neither primary nor secondary health care professionals possess the knowledge or skills required to undertake overall care of such families. This often results in families feeling dissatisfied by the delays taken at local hospitals in diagnosing the illness (Sloper 1996) or in feeling isolated, insecure and vulnerable in their local communities (Bignold et al. 1995a). It also creates a culture where professionals untrained in children’s cancer care may be perceived by families as ‘outsiders’ (Bignold et al. 1994a). This may be of particular importance during the provision of terminal care when primary care becomes the focus.

There have been several means of attempting to alter ‘shared care’ from a situation in which care is provided to children and their families by primary, secondary and tertiary health care services independently of each other, relying heavily on the family as the prime communicator between the three professional groups (Figure 2.2), to a condition in which professionals within these three organisations adopt a more integrated team approach (Figure 2.3). These have included devising ‘shared care’ cards onto which treatment, drug dosages and blood count results are recorded, which are carried by the patient from secondary to tertiary hospitals. An example of an early ‘shared care’ card used by the Haematology and Oncology Department at Great Ormond Street Hospital, London from the mid 1980s until the early 1990s is given in Appendix One. More recently patient-held records have been devised by a number of regional centres which are modelled on those which have been used within midwifery care. In addition to records of treatment and blood count results, patients are able to record their own information regarding effects of treatments and other influences on daily living activities (Hulley & Hyne 1993, Hooker & Williams 1996).
Figure 2.2 An Independent Approach to Shared Care between Primary, Secondary and Tertiary Health Care Settings
Figure 2.3 An Integrated Approach to Shared Care between Primary, Secondary and Tertiary Health Care Settings
The 'Raison d’être'\(^3\) of POONSs

Since the mid 1980s one solution to bridging the gaps between the primary, secondary and tertiary interface as an additional means of enhancing 'shared care' in which a 'seamless web of care' (Bignold et al. 1995a) has been the intention, had been to create a specialist nursing service, namely the paediatric oncology outreach nurse specialist (POONS)\(^4\).

POONSs emerged as a nursing specialty during the mid 1980s as a result of perceived gaps in services both by families and by health care professionals in paediatric oncology units. Posts have been established at either regional UKCCSG centres or DGHs with whom 'shared care' is practised. Whether POONS services originated at regional centres or DGHs has depended on the funding organisations with which posts have been associated. This is discussed in detail in Chapter Three in a review of NHS funding and the role of the voluntary sector. Early services were created to fill the greatest gaps and focused on supporting families caring for a dying child, who wished to remain at home. Other, later services were conceived to enhance 'shared care' between tertiary and secondary hospitals with the intention of enabling more DGHs to participate in a child’s care, particularly during chemotherapy. With services well established in the 1990s, it is the raison d’être of most POONS services to provide a 'seamless', supportive and educational network between tertiary, secondary and primary health care settings in which families are supported through all stages of a child’s 'cancer journey'. That is, families are cared for and consequently 'befriended' (Bignold et al. 1995b) by POONSs from the outset of a child’s disease, through to the eventual outcome, be it cure or terminal and bereavement care.

POONSs act as main contact persons to families in their own homes during periods of treatment and post treatment, most particularly following diagnosis. The amount of support required by families at this time may not be excessive but does require

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\(^3\) This term was first coined by Bignold et al. (1994a, 1994b)

\(^4\) Formerly referred to as the Paediatric Oncology Community Nurse Specialist (POCNS).
specialised skills and knowledge to help them gain confidence to care for the sick child whilst readjusting to their normal pattern of family life (Hunt 1996).

If all treatment options fail, the emphasis of care will be focused in the community. The POONS’s role becomes central to the child’s terminal care and they are able to offer PHCTs their expertise in caring for children dying from cancer. During this time POONSs act as a central link for families to their treatment centre and relationships which have often built up with POONSs over the preceding months are greatly valued (Bignold et al. 1994a, 1994b). This relationship may extend beyond the death of the child when bereavement support is usually offered to families by POONSs. The ways in which these services are provided and the extent to which they are shared with other health care professionals vary and are the subject of this study.

**The Child with Cancer - An Extreme Emotional Challenge**

Nursing adults with cancer, particularly when newly qualified, produces feelings of negativity and inadequacy (Corner 1988, Corner & Wilson-Barnett 1992). Compounding this, nursing the dying has been recognised for as long as thirty years as an area of work which may produce intense and unmanageable anxiety when faced with distasteful and distressing tasks (Menzies-Lyth 1960). More recently Maguire (1985) observed that both doctors and nurses caring for terminally ill patients employ distancing tactics which prevent them from becoming emotionally close to patients. Terminal care has further been described as an area of nursing which gives rise to ‘emotional labour’ (James 1992); taking this a step further, it has been referred to as the ‘ultimate emotional labour’ (Smith 1992). Furthermore, irrespective of training, nurses working in palliative care experience great stress when patients endure intractable pain, have young children, are afraid to die or die unexpectedly from an acute episode; junior staff also encounter stress when unsupported by senior colleagues (Alexander 1990, 1993). For those who experience personally stressful events outside work, the ability of nurses working in hospices to maintain boundaries between their professional and personal lives may become compromised (Froggatt 1995).
Less is understood about the effects of a child's death on health care professionals. Stein and Woolley (1994) have reported that staff who work in a children's hospice find the death of a child particularly distressing when s/he has deteriorated to a level where s/he no longer recognises those around him/her and when there is no perceived quality of life. Staff in their study also found being excluded from a child's care when they had long been central carers a stressful experience. The lack of experience and availability of a peer group support system encountered by one student nurse, traumatised by the death of a child involved in a road traffic accident, led her to almost quit nursing (Anon 1993).

In contrast, a small scale qualitative study which examined the causes of stress for nurses working in a paediatric oncology/hematology ward suggested that the terminal illness and resulting death of a child was not the most stressful component of their work (Harding 1996a, 1996b). It must be acknowledged however that since the late 1980s few children with cancer have died in hospital, with POONS services influencing families in this choice (Beardsmore & Hunt 1990, Beardsmore, Goldman & Hunt 1990, Hunt 1991, Goldman 1992, Thompson 1996) and PCN services assisting in this process (Godfrey 1996). Thus contact with dying children by ward-based nurses, is minimal. Indeed the presenter of a recent case study at the 1996 annual PONF conference suggested that nurses feel stressed when they encounter the rare event of the death of a child on a ward not because of the child's death per se but because of a sense of failure experienced through not enabling a child to die at home (Hall 1996). Hall suggested that junior nurses experienced stress when a single parent, alone in a foreign country and homeless, had chosen to remain within the specialist unit to care for her terminally ill son. It appears from this case study and from other anecdotal evidence that the author is aware of, that junior nurses working in paediatric oncology units, indoctrinated with the evidence that home is the preferred choice of most parents to care for their dying child, encounter stress when they are unable to achieve home as the location for a child's death, even when it has been the parental choice to do otherwise.
The involvement by POONSs in a child’s terminal care has been described elsewhere as one of emotional labour (Bignold et al. 1995a). In caring for children at home and befriending families POONSs are required: ‘not only to deal with other people’s feelings, but also to deal with their own’ (Bignold et al. 1995a:77). This involves a process whereby POONSs become emotionally involved with families whilst at the same time retaining some emotional distance. This process and the emotional labour involved is complex and difficult for POONSs themselves to describe (Bignold et al. 1995a).

Little is known about the emotional stresses put upon PHCTs when caring for a dying child. Hindmarch (1994) however, has suggested that GPs, due to their traditional professional independence, may find it hard to seek professional support and advice from others when confronted with the death of a child, whilst HVs may feel apprehensive of the emotional turmoil of the bereaved family. From these limited findings it is possible to surmise that health care professionals, such as POONSs and children’s hospice staff, more used to and experienced in paediatric palliative care, will endure no more stresses than those more familiar with caring for dying adults and that a child’s death becomes stressful to staff experienced in paediatric palliative care, only in the face of a ‘difficult death’. Those inexperienced in paediatric palliative care or untrained to work with children, who encounter the death of a child rarely, such as PHCTs, may find a child’s death beyond the ‘ultimate emotional labour’ (Smith 1992) to become an extreme emotional challenge.

Health Care Policy and the Sick Child
The concept of a hospital for sick children arrived late within the history of the development of acute hospitals and the first hospital for sick children was opened by the physician Charles West, at Great Ormond Street Hospital in London, in 1852 (see Chapter Three for further detail). The establishment of a hospital for sick children was controversial since, prior to its inception, it was considered by health care professionals that sick children were best nursed at home by their mothers in the company of their families (Saunders 1982, Miles 1986a, Lomax 1996). For more than half of the early part of the twentieth century, for a child to be admitted to hospital
was a particularly traumatic experience for both a child and his/her family:

For many years, to have a child admitted to hospital was to surrender the child to the nursing and medical staff completely. The child admitted to an infectious diseases hospital was abandoned by his parents to white shrouded attendants - ghoulish figures to the fevered imagination of a child - and not rescued again until he was completely recovered which could be a matter of weeks or months, according to the degree of complexity of the disease. The only visiting that was allowed was if the child’s name appeared on the ‘danger list’, when it was unlikely that either the child or parents would recognise each other (Saunders 1982:143)

Two major studies undertaken in the 1950s revealed the emotional traumas suffered by children, separated from their mothers through hospitalisation (Bowlby 1951, Robertson 1958). From this time forward policies and practices of caring for sick children have changed, opinions reverting to those of the early 1800s with: ‘the circle [having] turned fully... to some of the ideas, ideals and attitudes of a century ago’ (Saunders 1982:143). Since the publication of the Platt Report (Ministry of Health 1959) it has generally been acknowledged that, where possible, sick children are best nursed at home by their families, with any required professional intervention being given by suitably qualified sick childrens’ nurses. However the publication of the Court Report (DHSS 1976) more than fifteen years later, in which one of the main recommendations was that children should be looked after by nurses with special training in identifying and meeting their needs as well as those of their families, revealed that few sick children were nursed at home by RSCNs. Nearly 40 years after the publication of the Platt Report, the government have recognised that all sick children have the right to be nursed at home by RSCNs (DoH 1996a, House of Commons Select Committee 1997) and that this is consistent with good practice (DoH 1996b); however fewer than 50% of sick children currently have access to such services with less than 10% covered by 24 hour provision (Godfrey 1996).
The way in which services have been provided to sick children nursed at home, by RSCNs has varied. The majority of services have been provided as ‘outreach’ services, established as an extension to ward and out-patient department (OPD) facilities, located at DGHs, providing generic services to all sick children discharged from hospital. These services are referred to as paediatric community nursing (PCN) services. Fewer PCN teams have been based within the community (Whiting 1988, 1989). A few early PCN teams were established during the 1950s including teams in Rotherham, Paddington and Birmingham (Whiting 1994). However, archival material at Great Ormond Street Hospital for Children NHS Trust (GOS), suggest that the earliest example of a home visiting scheme operated from the hospital from 1859. In a study undertaken in 1988 only 23 PCN services existed in England (Whiting 1988). Since this time there has been substantial growth in PCN services and between 1993 and 1995 the number of schemes grew from 61 to 88 (Whiting 1993, 1995).

It has been suggested that one of the problems with the slow expansion of PCN services concerned the difficulty in procuring funds to establish such services. Whiting (1988, 1989) highlighted the difficulties that existing services had in expanding their teams, due to a lack of funds. He also reported that current funding for PCN teams had been procured from a variety of hospital, community units, regional monies and local GP budgets.

An additional way in which services have been extended by RSCNs, to sick children being cared for at home, has been through the establishment of specialist, rather than generic paediatric nursing services. These services have tended to be disease specific although do include a number of services provided to groups of children such as neonates (Whiting 1995). In contrast to PCN services, specialist services, such as those provided by POONSSs, have rapidly grown in numbers and 57 specialist nursing services were reported in England in 1995 (Whiting 1995). In proportion to the numbers of sick children cared for at home, the number of specialist services are higher than those provided by PCN services. Many of these posts have been established at regional rather than district hospitals and there expansion has been aided through the backing and financial support of families. Indeed Goldman and
Baum (1994) reported that the majority of specialist paediatric nursing services which existed by 1988 in the UK, unlike generic PCN services, had been established with the financial support of charities (for further detail see Chapter Three).

Inspite of continuing government policies to recognise the importance of caring for sick children at home, the recent growth in PCN services and the number of specialist nursing services which currently exist in England, a recent study undertaken by While et al. (1996) suggested that there were many families within the UK caring for children with life-limiting, incurable disorders, whose domiciliary support needs were unmet. The findings from their study have contributed towards a recent publication in which it is recommended that a co-ordinated approach to terminal care be implemented within each district health authority, where a senior paediatric professional (nurse or doctor) be available (ACT/RCPCH 1997). In this report however, it is has been emphasised that the needs of children with malignant disease and their families, have largely been satisfied through POONS services.

Hence, whilst there are still gaps in services for some sick children with diseases other than cancer, current policies pertaining to the care of sick children in the community are largely achieved for children with malignant disease and their families through the establishment of POONS services.

**The Clinical Nurse Specialist**

**The Origins of the Clinical Nurse Specialist**

Specialists in nursing are not new. Castledine (1994) has argued that the creation of specialist nursing practice began during the Nightingale era with both the establishment of the Florence Nightingale School of Nursing and with the publication of her second version of *Notes on Nursing*. These two initiatives, he suggests, identify and link nursing as a profession with that of a specialty in which two classes of nurse are described: the amateur and the professionally prepared hospital nurse. As early as 1910 nurses were designated as specialists in North America (Hamric 1989a), whilst in the UK nurses such as ‘Sister Dora’ became famous during the 1870s for her specialised nursing treatment of machinery accident victims in Walsall (Manton
1971). Such injuries were the result of the increasing number of industrial accidents which occurred due to poor working conditions in the rapidly expanding industrial Black Country; patients were cared for by Sister Dora in such a way that new nursing interventions were introduced which, in the severest of cases, prevented patients from otherwise amputating surgery. For the first half of the twentieth century the term 'specialist' denoted a nurse with extensive experience in a particular area of nursing (Hamric 1989a). It is however more generally considered in the history of nursing that the concept of 'CNS' is fairly young, emerging in North America and spreading to the UK during the early 1970s.

It has been suggested that the concept of a specialist in clinical nursing evolved in North America when the term 'nurse clinician' was first adopted in 1943 (Storr 1988). Others have considered that the CNS title dates back to 1938 (Peplau 1965) whilst elsewhere some confusion reigns as to the origins of the title (Hamric 1989a); it is agreed nonetheless that the title's beginnings arose in North America, during the late 1930s or early 1940s. More generally however the label CNS began to appear in the 1960s when, in North America, much of the early literature focused on the justification for Masters level education for advanced clinical practice; it has long since been a prerequisite of achieving CNS status that Masters level education be attained (Storr 1988, Hamric 1989a, Fenton 1992). Of particular note, cancer nursing developed graduate education specialisation programs at an early stage in the evolution of the North American CNS (Hamric 1989a). In parallel, whilst Masters level education remains nonessential to attain CNS status in the UK, the earliest British CNS posts were also developed in cancer nursing, at the Royal Marsden Hospital in London (Castledine 1994).

Castledine (1982, 1983, 1994) first addressed the issue of the rise in specialist nurses within the UK, suggesting that this occurred in response to an increase in public demand for services, an expansion of knowledge and skills, both in medicine and in nursing and particularly in technological interventions, and a desire by nurses for a more varied career structure. Early CNS posts within the UK sometimes involved taking on skills originally the domain of doctors, whilst others developed new skills...
to cope with new patient problems (Castledine 1994). More recently similar theories have been assigned to the emergence of the ANP (e.g. UKCC 1994, Cassidy 1996, Chan 1996, Dowling et al. 1996). In addition to these developments, and of particular poignancy to this study, it has been said of the development of specialization in North American nursing, that funds are often made available for specific (i.e. specialised) areas of practice (Hamric 1989a).

In as much as the developing CNS role responded, in part, to increased technological advances, it has been argued that changes in specialist nursing practice in paediatric settings in North America, have occurred in response to the overall decrease in mortality rates and an increase in childhood morbidity, brought about through such technological advances (Lipman & Deatrick 1994). The increase in survival from previously life-limiting or life-threatening diseases\(^5\) means that children have complex, ongoing educational, health, and social needs. For such families paediatric CNSs will see them at times of major transitions in their treatment when they may be: *'most amenable to intervention'* (Lipman & Deatrick 1994:58). In the UK new specialist posts in paediatrics have more commonly be associated with parental initiatives, establishing services to provide specialist support for families whose children have rare conditions with which PHCTs are frequently unfamiliar. Other services have been the response to bridging the communication gap between hospital and community nursing staff (Kitson et al. 1987). The POONS is probably the best example of established paediatric CNS posts although other specialist areas have more recently emerged. The CNS for the child with Cystic Fibrosis is one such example (Glew 1993) although five forums and nine special interest groups existed for child health nurses within the RCN in 1996.

\(^5\) The Association for Children with life-threatening or Terminal conditions and their families (ACT) have distinguished life-limiting diseases as those from which children will inevitably die whilst life-threatening diseases pose uncertainty as to their outcome.
Role Definition

Although extensive studies have been and continue to be undertaken in the USA concerning the work of CNSs (e.g. Harrell & McCulloch 1986, Malone 1986, Ingersoll 1988, Steele & Fenton 1988, Hamric & Spross 1989), to date limited studies examining the role of the CNS have been undertaken in the UK. A number of evaluation studies have been carried out pertaining to the fields of community nursing, terminal care, continence advice, HIV/AIDS, diabetes, and stoma care. These have highlighted both the benefits and problematic areas arising from the role of the CNS and will be drawn upon in later chapters to discuss interprofessional and intraprofessional relationships (for example Haste & Macdonald 1992, Charlton & Macaulay 1993, Rhodes 1993, Layzell & McCarthy 1993, Wade & Moyer 1989, Cox, Bergen & Norman 1993).

In his earliest study into CNSs, Castledine (1982, 1983) identified 11 key aspects to the role of the CNS to which no single CNS fully satisfied, these comprised: direct involvement in care, responsibility and accountability for nursing actions, to be highly educated, a researcher, an educator, a co-ordinator of care, an expert in both clinical assessment of patients and in her field, to be autonomous, to be a writer and to form a liaison between the community and the hospital. This multiplicity of roles is consistent with a later survey conducted by the Daphne Heald Research unit of the RCN in which it was reported that 1,016 CNSs nationally held 82 differing job titles (Wade & Moyer 1989). In a review of the literature during a similar period, Storr (1988) highlighted six components to the CNS role, these comprised: practitioner, educator, consultant, researcher, change agent and staff advocate. In addition, domains and competencies which constitute advanced clinical practice within the CNS role, have been examined in the American literature (for examples see McGee et al. 1987, Fenton 1992). Extensive studies in the USA have more recently examined individual components of the CNS role; examples include focusing on the staff educator role in which the responsibilities of CNSs working with nurses in a cancer setting and teaching methods are explored (Bakke 1992), the ‘caring’ role (Schaefer & Lucke 1990) and the increasing importance of clinical decision-making and coordination of care have also been focused upon (Lipman & Deatrick 1994).
Underpinning most studies however, is the continuing confusion about the definition of CNS roles. As Steele and Fenton wrote in 1988:

*Even though the role of the clinical nurse specialist (CNS) has been described in educational criteria, standards and the literature some confusion still exists about the essential clinical practice skills needed for this advanced role. This situation may be due to the wide diversity of roles that CNSs assume in health care settings. In one institution a clinical nurse specialist may be involved primarily as an educator, in another as a consultant, and in another as an administrator or researcher or some combination of these roles*  

(Steele & Fenton 1988:45)

The emergence of the ANP role in the UK in recent years reflects the continuing confusion regarding the CNS role and delineation between the two roles is indistinct (e.g. Castledine 1996, Castledine et al. 1996, Coyne 1996, McGee et al. 1996, Mills 1996). However a recent British review of the literature has suggested six major components to CNS roles to which many health care professionals currently subscribe, these comprise: clinical expert, resource consultant, educator, change agent, researcher and advocate (Miller 1995). For the purposes of examining the work of POONSs, this study will focus on these six components.

**Personalities of Clinical Nurse Specialists**

Little work has been undertaken which explores the personalities of CNSs. However a large scale Delphi study undertaken in the States which examined the competencies of CNSs working in oncology, revealed that health care professionals working with such CNSs placed their attitudes and human traits above other competencies, including their knowledge and skills (McGee et al. 1987). In particular, maintaining ethical practice and showing respect for humanity scored highly as valued traits of CNSs working in cancer care. These qualities were encompassed into the important aspects of caring, commitment and professionalism.
In her literature review on the role of the CNS, Storr (1988) compares the personalities of CNSs with other nursing colleagues. She suggests that Calkin (1984) considers CNSs to have greater and more rapid intervention skills than their colleagues which earn them a reputation of 'expert', whilst Mallison (1984) talks of 'splendid mavericks' who have refused to step away from patient care. In addition, Storr suggests that an important attribute of the CNS is to possess charisma or referent power; this type of power she suggests, comes largely from positive interpersonal skills. In possessing such skills she adds that CNSs have the ability: 'to sense how to make the system work by working around problems rather than shattering themselves to bits against immovable objects' (Storr 1988:267). In further discussion concerning interpersonal skills and of particular significance to this study, POONSs have been described as possessing particular interpersonal skills which enhance their ability to provide 'a seamless web of care'. Here, tact and diplomacy are of paramount importance when crossing professional boundaries between the specialist centre and the local community (Bignold et al 1995a).

Most common however of all personality traits, CNSs have frequently been described as entrepreneurial with dynamic personalities and possessing excellent communication skills (e.g. Riehl & McVay 1973, Hamric & Spross 1989, Hazelton et al. 1993, Miller 1995, Arnfield 1996). Given that the CNS rôle is relatively new, that CNSs may have been responsible for establishing the service with which they are associated (e.g. Hunt 1996) and that CNSs communicate across a wide network of professionals, it is not surprising that such attributes have been associated with CNS personalities. Since this research sets out to examine professional relationships between POONSs and other health care professionals with whom much communication may be required, the importance of the CNS 'personality type' cannot be underestimated.

The Future of Clinical Nurse Specialists

As with many new initiatives in nursing, particularly regarding nurse education, they migrate to the UK from North America. Earlier in this chapter it was suggested that it has long been a prerequisite of the North American CNS to be educated to Masters level (see The Origins of the Clinical Nurse Specialist, pages 24-26). Although it has
been recognised in the UK since the last decade that nurse specialists: 'are prepared beyond the level of registration' (RCN 1988:6), distinctive criteria regarding educational levels of CNSs have remained unspecified. Moreover, educational attainments of CNSs have varied and jobs frequently developed around the experiences of individuals (Smith 1990). Whilst the United Kingdom Central Council for nursing, midwifery and health visiting (UKCC) has recently recommended that nurses wishing to enter a specialty (as distinct from becoming a specialist i.e. 'expert') be appropriately trained within the specialty (UKCC 1996), there remain no stipulations for attaining specialist status. Nonetheless the author is aware that an increasing number of CNSs have recently undertaken or are undertaking Masters and PhD level education. Pressures have been felt by some to consider the importance of higher education as they increasingly feel outdone by more highly educated yet more junior colleagues who achieve graduate status (Hunt 1994). In addition, pressures are sometimes being applied to CNSs to undertake Masters level education from managers. An example of this was a directive issued from senior nursing management at GOS in 1992, requesting all CNSs achieve Masters level status within five years; it was this directive which led me as a CNS working at the hospital, to undertake this PhD.

Since the early 1990s the development of advanced practice in nursing, embodied within in the CNS role, has troubled CNS identity in the States; furthermore, downsizing of workforces has led organisations to reduce or eliminate CNS positions all together (Hamric 1992). Such actions, Hamric (1992) suggests, indicate that institutions do not see CNSs as part of the solution to care delivery problems. Downsizing, she continues, has failed to recognise the importance of the CNS role in supporting and better structuring the staff nurse role with nursing shortages being supported by, and increasingly replaced with, non-professional staff.

One solution for the future of the North American CNS, which has been considered for the past ten years, has been to suggest that the CNS and ANP roles merge (Fenton 1992, Hamric 1992). This has resulted in ANPs following patients throughout the course of their hospitalisation and beyond (Hamric 1992). This appears to reflect
the current practices of POONSs, thereby suggesting that either the ANP role is already merging with the CNS role in this country or that CNS roles in the UK differ to those in the USA. In contrast, Lipman & Deatrick (1994) have suggested that merging the role of the ANP with that of the CNS is not proposed since there are differences between the primary and specialty (i.e. tertiary) orientations to practice. This problem is exacerbated in the USA by graduate educational programs which, it is argued, does not prepare graduates in both areas.

The recent experiences of ‘downsizing’ the nursing workforce in the States are reflected in current managerial changes in the British health care system. Particular effects for CNSs have concerned the clinical grading structure. Since the implementation of the current clinical grading structure in 1988, recent downgrading of senior nursing posts has aroused much interest (for example see Gavin 1995). This has had implications for all senior nursing grades, including CNS posts. An example of this has been illustrated through my own previous POONS post. During the restructuring of the clinical grades in 1988 my position with the SCT at GOS was graded ‘H’. On quitting the post my replacement was offered a ‘G’ graded position whilst a more recent appointment to the team was only offered an ‘F’ grade, thereby eroding the CNS status. Similar occurrences have been observed through recent job advertisements (Nursing Times 1996, 1997).

With the gradual erosion of the CNS post and increased interest in the ANP role, it is probable that the current lack of clarity between the two nursing roles (e.g Castledine et al. 1996) may increase. This raises questions for both the future of the ANP and the CNS role; we can only continue to observe the future of both roles in North America, unable to speculate the future development of both roles in the UK. However it would appear from the literature and from personal observations, that the future advanced practitioner, be she CNS or ANP, has an uncertain future whilst continuing to become increasingly educated.
Conclusion
This chapter has discussed the nature of malignant disease in childhood. In so doing it has described its management and the implications of care delivery for children, their families and health care professionals providing for them. It has examined the effects of a child’s death upon health care professionals suggesting that, for those unused to providing terminal care for children, untold emotional stress may be placed upon them. These sections of the chapter set the scene for the context in which the POONS nursing specialty arose, suggesting that terminal care is central to their work. The chapter has highlighted the differing developments between POONS and PCN services. It has emphasised the important roles which both groups of outreach nurses play in attempting to achieve current policies relating to community care for sick children. This chapter has also illustrated the difficulties in defining the CNS role and these difficulties will be drawn upon later in the thesis to discuss the implications for different models of POONS practice. In particular, the requirement by CNSs to attain further post registration education and to be highly educated will be discussed in greater depth in Chapters Four and Ten when debating ‘specialist knowledge’. The stresses placed upon those rarely required to provide terminal care and the personality types of POONSs, it will be shown later in this thesis, have important implications for the way in which relationships are constructed with other health professionals.
Chapter Three - Who Pays for Health Care? - A Review of Funding Provision of the British Health Service

Introduction

It has been suggested that obtaining funds to establish new, specialist services such as terminal care support teams, is frequently difficult to achieve from central funding sources (Dunlop & Hockley 1990). In particular Goldman and Baum (1994) proposed that the majority of specialist paediatric nursing services, unlike generalist paediatric community nursing services, which existed in the UK by 1988 have been funded from charitable sources. Charitable organisations have consequently played a large part in financing and establishing the work of POONSs; over three quarters of posts have been financed by charities at some time (Hunt 1994, 1995). This research sets out to analyze the impact that voluntary sector funding has upon the organisation, structure, work and professional relationships of CNSs, taking POONSs as an example. This chapter will therefore examine the role of voluntary funding within the mixed economy of health, focusing particularly on nursing services in the UK. It will also discuss the charities associated with POONSs.

In this chapter the changing role of the voluntary sector within health care will be illustrated, examining historical and contemporary policies. In the light of contemporary health care policies the implications for present day specialist paediatric nursing services will be explored. It will be demonstrated that the once important voluntary sector in health care prior to the establishment of the NHS, has once again in the 1990s, an increasing role. Such increases in voluntary sector funding move from what has been described as an 'institutional' model of care where public health care services are provided as 'normal', 'first-line' functions of modern industrial society (Wilensky & Lebeaux 1965, Higgins 1986, Mayo 1994), towards a 'residual' model. This operates only when the 'normal' market structure breaks down, resulting in provision by the voluntary services or private sector, with minimal state intervention (Wilensky & Lebeaux 1965, Higgins 1986, Mayo 1994).
The Development of Hospital Care - An Historical Perspective

It is generally considered that modern health care dates back about two hundred years when the use of effective medicines such as morphine, quinine and atropine closely followed the discovery of the smallpox vaccine by Jenner, in 1798. In parallel, rapid accumulation of a body of scientific knowledge accompanied discoveries in anatomy and human physiology (e.g. see Abel-Smith 1976, Dingwall et al. 1988, Baggott 1994, Baly 1995). At this time and preceding this, care was provided mainly by family members, usually women, in the home or by other voluntary members of the community with a reputation for healing. Medical attendance varied according to one's social status; hospital care was provided to a few wealthy people in voluntary hospitals, which relied either on subscriptions from affluent members of the community, or in some instances, endowments. Poorer members of the community requiring medical attendance, unable to pay for it, relied upon a series of acts collectively known as the Poor Law which dated back to Elizabeth I, and were cared for in public hospitals (Dingwall et al. 1988). Sick children were nursed at home (Saunders 1982, Miles 1986a, Lomax 1996).

The rapid expansion of medical knowledge during the nineteenth century was aided by the gradual acceptance of scientific experimentation; greater understanding of diseases such as communicable infections thus developed (Baggott 1994). This led to an increasing demand during this time to isolate patients with infectious diseases, and also to confine the mentally ill. This led to an increase in the demand for hospitals but for different reasons, in separate institutions.

Whilst the majority of the sick were institutionalised in publicly owned institutions and 'Poor Law' hospitals, the most prestigious hospitals and the main teaching hospitals were established and maintained through charitable donations (Abel-Smith 1976). These 'voluntary' hospitals in addition, were often founded in buildings donated by wealthy individuals or organisations. It was not until the end of the nineteenth century that some of the voluntary hospitals began to make charges to their wealthier patients. Many more however continued to give their services free of charge reflecting their voluntary status (Abel-Smith 1976, Baggott 1994). Voluntary
provision dominated health care services in hospital and community care until the
First World War, when increasing technology, especially in the field of surgery,
resulted in an increase in public or 'Poor Law' hospital care. Dingwall et al. (1988)
suggest that the Emergency Medical Service stipulated all designated hospitals receive
casualties of war regardless of their status. This resulted in voluntary hospitals rapidly
relying on government subsidy (Dingwall et al. 1988). By the outbreak of the second
world war increasing numbers of patients were being cared for in the voluntary
hospitals with only a third of their income received from charitable sources. Patients
were increasingly charged and health insurance policies increasingly necessary (Abel­

The Development of Hospitals for Sick Children
Hospitals established to care for sick children have roots similarly grounded within
the voluntary sector. Although other hospitals for sick children had opened in Europe
earlier, the first sick children’s hospital in the UK to be opened was in 1852 by the
physician, Charles West at Great Ormond Street, London (Saxton 1981, Saunders
1982, Miles 1986a, Lomax 1996). Earlier scepticism had hindered such hospitals
from opening since it was debated amongst the medical profession that not only was
it better for children to be cared for at home, but also the high childhood mortality
rate from infectious diseases would dissuade charitable organisations from donating
funds (Burr 1987, Lomax 1996). Moreover the expense of one-to-one nursing
required to nurse children, would be prohibitive (Saunders 1982). Following much
campaigning by Dr. West such anxieties proved unfounded and the concept of a
hospital for children was finally established. The support and an appeal made by

Other specialist hospitals for children soon followed the first at GOS, such as the
Infirmary for Children which opened in Liverpool in 1856, the Free Hospital for
Children in Nottingham in 1869 and the Glasgow Hospital for Children in Garnethill
in 1883, to name but a few (Brewis 1981, Miles 1986a, Lomax 1996). All relied
upon public subscriptions donated from local campaigns which were initiated by
surgeons or physicians and appear to have been raised with similar ease.
As with the voluntary hospitals established to care for the sick adult population, voluntary organisations associated with the establishment of hospitals for sick children were responsible not only for the provision of the buildings which housed the sick but also for the training and salaries of the nursing staff (Miles 1986b).

By the turn of the century the demands upon the voluntary hospitals specialising in sick children outgrew the organisations’ abilities to cope with them (Miles 1986b). Larger premises were required by many of the children’s hospitals opened during the latter half of the nineteenth century (Lomax 1996). They were however still very dependent upon the good will of the local communities which they served. The children’s hospital in Nottingham for example was rehoused in a newly converted mansion house which belonged to a lace manufacturer. The Alder Hey Children’s Hospital in Liverpool which opened in 1914 was similarly initiated by the Clerk to the very wealthy West Derby Board of Guardians, responsible for managing valuable properties (Miles 1986b). In spite of the enormous demand upon the voluntary sector for childrens’ hospitals, they were constructed or reconstructed with the assistance of voluntary contributions until the implementation of the NHS Act in 1948. Since the inception of the NHS the majority of childrens’ hospitals have been gradually merged with DGHs although others have been upgraded and maintained as separate hospitals (Miles 1986b). Since 1948, the salaries and training of childrens’ nurses have similarly been funded predominantly through public sector financing. A few sick children however have continued to be cared for in the private sector.

The Rationale for a National Health Service

Following the 1914-18 War and during the Depression the voluntary hospitals faced increasing costs and a fall in donations (Baly 1995). This resulted in:

*a wide variety of fund-raising activities, with The Hospital Charity Ball becoming a feature of social life and the pages of the Tatler* (Baly 1995:161)
Nevertheless the voluntary hospitals were fighting for survival. Such activities, I would suggest reflect similar fund-raising frenzies today as hospitals within the NHS begin to rely more heavily upon voluntary donations.

Increased technological advances during and following the first world war led to greater numbers of public sector or 'Poor Law' hospitals. It also swelled the number of voluntary sector hospitals which resulted in a greater mixed economy. Britain's health care system prior to the establishment of the NHS was therefore rather complex and disorganised (Abel-Smith 1964, Baggott 1994). This complexity was augmented by the fragmented services shared between hospital, community and public health services with little coordination to tackle the more complex needs of vulnerable groups, such as children. In addition, fragmentation of health care was the result of inequality of service provision - the National Insurance Act of 1913 neglected the needs of sections of the population such as those needing specialist services. Furthermore the growth in health insurance necessary to pay for hospital services, resulted in health care being dependent on the ability to pay (Abel-Smith 1976, Allsop 1984, Baggott 1994). Thus a mixed economy of health care had been firmly established through parliamentary policy; this continued up to and beyond the birth of the NHS with collaboration between private and NHS hospitals: NHS patients often treated on a contractual basis at private hospitals (Mohan 1991).

The rationale behind the NHS was therefore to provide health care to all those in need, which was to be free at the point of entry and to allow for more effective planning of services. This meant that financial responsibility for health services was centralised at government level (Allsop 1984). The previously complex mixed economy of private, public and voluntary sector funding was therefore diminished following the implementation of the NHS Act in 1948. The first twenty five years of the NHS established itself as a major component of the welfare state (Black 1995).
The Impact of the Voluntary Sector on the Development of Nursing

The origins of nursing are diverse and are reflected in the specialties of today, for example children's nursing, mental health nursing, adult nursing and community nursing (Abbott & Wallace 1990). Such specialties are deeply entrenched within the voluntary sector - welfare evolved through stages in which the church, the family and voluntary organisations were the main providers (Higgins 1986).

Although Abbott and Wallace (1990) suggest that paediatric nursing, like other specialties has its own history, discussions concerning such origins do not appear in the sociological literature. However, the development of paediatric nurse education is discussed in the nursing literature, whilst medical and psychological literature focus on child care policies and the needs of sick children and their families (e.g. Bowlby 1951, Robertson 1958, Ministry of Health 1959). Much of the work of POONs is focused on the community. Therefore in order to maintain a balance between the sociological and nursing literature and to reflect two of the major nursing specialties which POONs embrace, both the history of community nursing and the evolution of paediatric nursing will be discussed, reflecting the significance of voluntary sector input in their development.

Community Nursing

Community nurses have been defined as: 'nurses working outside hospital who have been fully prepared through training and education for the clinical responsibilities needed to deliver primary health care in the community' (Ross & Mackenzie 1996:x). Community nursing comprises HVs, DNs, school nurses, practice nurses, community psychiatric nurses, community mental handicap nurses, occupational health nurses and a range of specialist nurses (NHSME 1993b). Paediatric community nurses have been overlooked in the National Health Service Management Executive's (NHSME) definition although I would suggest they are an important component of primary care.

The origins of paediatric community nursing are strongly linked with hospital-based paediatric care (Tatman & Woodroffe 1993). However, the derivations of most community nursing traditionally lie in the two former groups - health visiting and
district nursing. Dingwall et al. (1988) suggest that the history of district nursing traditionally begins with William Rathbone who initiated and funded a home nursing scheme in Liverpool during the mid 1800s. Rathbone was the first to coin the phrase ‘district nursing’. However the concept was not new since:

*Associations for the provision of nursing care to the poor had been in existence some twenty or thirty years earlier under a variety of religious auspices* (Dingwall et al. 1988:174)

In addition, earlier provision of ‘nursing’ care by local community volunteers could conceivably be considered as an early form of district nursing. Indeed, in discussing the development of both district nursing and health visiting, Dingwall et al. argue that the modern shape of these two nursing specialities lie in the: ‘professionalization of voluntary effort’ (Dingwall et al. 1988:180).

Rathbone’s scheme in Liverpool was soon followed by a similar one in Manchester (Dingwall et al. 1988, Baly 1995). This was established in 1864 by the Manchester and Salford Ladies Sanitary Association who were ‘ordinary working class women’, referred to as ‘mission women’ (Dingwall et al. 1988). They were paid by the mission until 1907 when the local authority assumed responsibility for the service and decided to restrict future appointments to trained nurses. The responsibility for the ‘mission women’ was governed by ‘lady volunteers, in charge of the district’, often regarded as the first health visitors.

Major social influences such as improved sanitation and housing, in addition to nursing activists, reformed nursing during the mid 19th century. Such developments occurred predominantly through religious orders such as the Sisterhood of Mercy of Devonport and Plymouth who dedicated their lives to the causes of social reform and improvements in sanitation and health care (Dingwall et al. 1988). Florence Nightingale was greatly impressed by such religious enthusiasms of the time and was immensely influenced by them (Dingwall et al. 1988, Selsdon 1994). She was able to volunteer and dedicate her time in developing nursing still further. This she was
able to do with the advantage of her background:

William Nightingale [her father] was a rich and well-educated gentleman with a serious interest in travel, scholarship and liberal politics. Fanny Nightingale [her mother] was the respected hostess of the salon of politicians and socially concerned intellectuals (Dingwall et al. 1988:36)

Voluntary contributions during the latter half of the nineteenth century assisted in establishing the nursing profession further, not only in the community but more generally. For example, the Nightingale Fund was initiated to provide education and employment for nurses and, until the recent implementation of Project 2000, was the base on which all nursing was grounded (e.g. Dingwall et al. 1988). An additional influence of the voluntary sector on the nursing profession concerns salaries. Prior to 1941 and ten years after The Lancet Commission had recommended that nurses pay: 'should be in accordance with the scales advocated by the College of Nursing' (Baly 1995:161), voluntary hospitals influenced the pay structure of the nursing profession, since each hospital was at liberty to pay its staff according to its own means. The College of Nursing in spite of its recommendations however, was in a Catch 22 situation; eager to negotiate for both conditions of service and salaries, it was aware that voluntary hospitals during the Depression, were desperately short of funds. Putting pressure on them to increase or standardise salaries would result in the voluntary hospitals applying for government grants which would result in the loss of their independence. During the 1930s the loss of independence was regarded as an anathema; it was the reason for the ten year delay in implementing the Lancet Commission report (Baly 1995). Thus voluntary sector influences fragmented nursing in relation to their salaries. This, I will argue later in this thesis, is not dissimilar to the voluntary sector influences on POONSs' grades today.

Paediatric Nursing

Paediatric nursing only emerged in the nineteenth century with the opening of the early childrens' hospitals (Miles 1986a). Although the criteria for opening the first children's hospital did not include the training of paediatric nurses, Miles (1986a)
argues that by introducing the first nurses to care specifically for children at GOS, the beginning of education and training of paediatric nurses was brought about. This was instigated by Charles West himself who suggested of nurses caring for children:

> if any of you have entered on your office without a feeling of very earnest love to little children, - a feeling which makes you long to be with them, to take care of them, - you have made a great mistake in undertaking such duties as you are now engaged in: the sooner you seek some other mode of gaining an honest livelihood, the better. I do not mean this unkindly, for you may be very good, very respectable women, and yet very bad nurses. You may be feeble in health, and then you will be unable to bear the confinement and the fatigue of attending upon the sick; or you may be fretful in temper, and may find your greatest trial to consist in the difficulty of subduing it, and in being as thankful to God for all his daily mercies, and as friendly with those whom you live amongst as you ought to be; or you may naturally have low spirits, and a child's prattle, instead of refreshing, may weary you. Now if any of these things are really the case with you, I would advise you not to be a children's nurse, and especially not to be a nurse in a Hospital for Sick Children

(West 1854:8-9)

Thus the organisation of GOS and similar early childrens’ hospitals financed by the voluntary sector, provided education and salaries for the first paediatric nurses. Hence, the voluntary sector assisted in the genesis of the specialty which later gained recognition through the Nurses Registration Act of 1919 (Castledine 1994, Porter 1995). Voluntary sector funding of paediatric nurses inevitably continued until the birth of the NHS, in a fashion similar to other branches of nursing. After this time voluntary hospitals and thus nursing, were increasingly funded through government sources. The voluntary hospitals became increasingly less voluntary, relying more on government grants and the establishment of funds such as the Hospital Saturday Fund (Baly 1995).
This section of the chapter has provided two distinctive examples in which the voluntary sector have contributed towards the construction of the British health care system. Firstly it has yielded examples of voluntary sector funding. This has been demonstrated through discussing the establishment and financial assistance in the running of voluntary hospitals. It has also been highlighted through the payment and training of 'nursing' staff, such as the 'mission women' of Manchester and Salford, the establishment of the Nightingale Fund and the creation of the first paediatric nurses. Secondly, voluntary sector influences on health care have been demonstrated through the donation of time. Examples cited have included the 'lady volunteers' of the Manchester and Salford Ladies Sanitation Association in their efforts to initiate health visiting services, the Sisterhood movement and their attempts to establish district nursing services, and Florence Nightingale. Since both the donation of time and of funding impacts on health care provision today, these will be discussed further in the following section. It is the voluntary donation of funds however which impacts directly upon the mixed economy of health care. These have consequences for POONSs, since it is voluntary donations which fund their services. It is this aspect of voluntary care which will be focused upon later in this chapter.

**Defining the Voluntary Sector in Health Care**

Before considering the voluntary organisations associated with POONSs, it is pertinent to pause here to contemplate the concept of 'voluntary'. Distinctions have been drawn between 'voluntary sector' and 'voluntary organisations' (e.g. Gerard 1983, Brenton 1985, Leat 1986). The 'voluntary sector' has been seen as any group, large or small, or individual offering unpaid assistance to those in need (Leat 1986:301). In contrast 'voluntary organisation' refers to unpaid help which is provided by organisations rather than by individuals or small groups (Brenton 1985:9).

In spite of these differences both concepts have in common the implication that services are provided to benefactors without direct financial reward to the providers. Brenton (1985) however argues that an element of profit-making, if not financial reward, is often associated with voluntary organisations since money may be raised.
through, for example, charity shops. Both concepts may be considered useful in relation to POONSs. These will be discussed later in this chapter.

Typologies of ‘voluntary organisation’ have been constructed. At its simplest Gerard (1983:35) classifies two types of voluntary organisation concerned with outcomes: order and change. Voluntary organisations have also been categorized according to their differing aims; they may be established because a need for a service is recognised, because mutual aid is required, a pressure group is developed, because a resource is needed or co-ordination wanted (Brenton 1985). Voluntary organisations established through a need to provide services:

*typify those voluntary agencies which supply a direct service to people, in kind or in the form of information, advice and support* (Brenton 1985:11)

Unlike Brenton (1985) who suggests that voluntary organisations are independent of government and self-governing, Leat (1986) contends that types of voluntary care cannot exclude statutory services. Voluntarization, which she argues is one form of privatization, may be closely linked to welfare provision with, for example, statutory services being provided for by voluntary funding. POONS services would be an example of this type of care. She therefore suggests that distinctions between funding, service provision and control or regulation of services are necessary variables to consider when focusing on non-statutory provision of welfare. Thus eight variants are described ranging from pure statutory where funding, service provision and control or regulation are provided by the state, to pure non-statutory services where funding, service provision and control or regulation, is provided for by the voluntary sector. Leat’s model would classify the voluntary organisations concerned with POONSs as: ‘subsidized statutory’ since statutory nursing services are provided by local authorities or trusts through non-statutory funding with either statutory or non-statutory regulation, depending on the funding and employing organisations concerned.
Charities Associated with POONSs

Having considered different perspectives of 'voluntary' and suggested that charities associated with POONSs are 'subsidized statutory' voluntary organisations (Leat 1986), this section of the chapter will focus on the charities related to POONSs. The majority of POONS services have been founded with the assistance of charitable organisations, which in the main, have been established by bereaved parents. Most of these have been initiated to create one-off POONS posts/services at treatment centres with which families have had close ties (Bignold et al. 1994a, Hunt 1994, 1995, 1996). Examples include the Sunset Trust, which was instituted by a small group of bereaved parents specifically to fund POONSs at one regional centre in the South East of England and LATCH (Llandough Aims to Treat Children with Cancer and Leukaemia with Hope) launched jointly in 1982 by both parents and their friends and medical staff in Wales; they similarly support the work of POONSs at a regional centre. The Christian Lewis Trust was also initiated by a bereaved parent to fund an individual POONS working at a DGH in Wales (Faulkner 1994). There have however been three main, larger voluntary organisations which have historically been associated with funding POONSs, in addition to the NHS. These are: the Rupert Foundation, CRMF and CLIC.

The Rupert Foundation: was formed in 1982 by Rupert's parents and was the earliest charity to be associated with funding POONSs at regional centres. Several early posts were established without much success and folded within twelve months of their creation. The earliest service to flourish was created at GOS in 1986. Other services which followed included teams at the Royal Victoria Infirmary, Newcastle established in 1987, at Southampton General Hospital and at St. Bartholomew's Hospital, London. The Rupert Foundation collapsed financially in 1990 and funding of established teams was taken on by CRMF in the same year.

The Cancer Relief Macmillan Fund: originally known as Cancer Relief, the charity was founded in 1911 by Douglas Macmillan, the son of a cancer sufferer (CRMF 1988). It was funded by subscriptions and interested individuals and concentrated on:
providing information on recognising, preventing and treating cancer to patients, doctors and interested members of the public (CRMF 1988:2)

In 1933 after nine years of being a registered Benevolent Society and distributing grants to patients, the first two ‘Nurse-Visitors’ were employed. Following the establishment of the NHS, the 1948 Cancer Relief’s summer bulletin suggested that in spite of legislation making provisions for cancer patients’ drugs, dressings etc. there would continue to be a need for a: ‘supplementary and personal service’ (CRMF 1988:2). This led to the establishment of hospice care before initiating the first Macmillan Nurse teams in 1975. The initial Macmillan nurses were established in areas where few specialist facilities for cancer patients existed (CRMF 1988).

CRMF now fund in excess of 1000 Macmillan nurses who predominantly work with adult cancer patients; in addition to the more recently established Macmillan Paediatric Nurses (MPN), they include Home Care nurses, Hospital Support Specialists and Breast Care Specialists (CRMF 1992).

CRMF entered childhood cancer care in 1990 (SCT 1990) following the demise of the Rupert Foundation. Since taking over the original ‘Rupert Nurses’, CRMF have been responsible for establishing an increasing number of new POONS services which are all ‘pump primed’:

This grant is given by the Cancer Relief Macmillan Fund for the development of Macmillan nursing services based on policies agreed between Cancer Relief Macmillan Fund and the employing authority. The grant is given for an agreed period, subject to the agreement that on expiry of the grant the employing authority will continue and maintain the service specifically for the purposes

1 Formerly referred to as Paediatric Macmillan Nurses (PMN), the use of the word ‘Macmillan’ now fronts the title to conform with other Macmillan nursing posts.

2 ‘Pump-priming’, sometimes referred to by other charities as ‘kick starting’, may be defined as contributing money into the NHS for a finite length of time, after which the funding of the nursing posts is taken over by the employing authority.
Cancer and Leukaemia in Childhood: was originally established in 1976: 'to build a first-class regional service for children with cancer and their families..... it would be a trust that would grow and one day be able to embrace all afflicted families' (Woodward 1990:14). The charity was founded to provide funds for three dimensions of childhood cancer care within the South West region; research, treatment and welfare. In particular, emphasis was given to welfare, primarily to provide accommodation for families from the SW of England whose children underwent treatment at the regional centre in Bristol, and who were required to stay many miles away from home (Woodward 1990). They also provide funds for other activities including research laboratories and Clinical Research Fellows, a play therapist, crisis-break accommodation for families and an ambulance service (Woodward 1990).

Expansion of the charity's ideals led to the establishment of a domiciliary nursing service during the 1980s which has subsequently taken prime position in CLIC's objectives. More recently since the outset of this study, 1994 saw both a national and an international expansion of their services, working particularly with hospitals in Russia. CLIC also fund several Associate Specialists in paediatric oncology to work alongside CLIC nurses and the only paediatric palliative care consultant currently in post in the UK. Although initial posts and more recent positions have been funded for an indefinite period of time, others have been 'pump-primed' in the same fashion as Macmillan posts.

Funds for POONS services, irrespective of the charity, are provided by reimbursing the local authorities/hospital trusts, for their costs. Charities in turn, rely on voluntary donations from individuals, trusts and companies. Charities funding POONSs depend

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3 The Whitley Council define an Associate Specialist as a medical practitioner who has served a minimum of four years in the registrar or staff grade, at least two of which have been in the appropriate specialty. The practitioner should also have completed ten years medical work since obtaining primary medical qualification. The appointment is 'ad personam' with no on call commitments and no automatic replacement on leaving.
on additional means of generating income such as those suggested by Brenton (1985), including investment or, in the case of the larger organisations such as CRMF and CLIC, trading through charity shops.

Since it is the aim of this study to examine the influences of the strategies of various funding organisations associated with POONSs, those POONSs who were originally funded by the Rupert Foundation have been categorised during the course of the data analysis, within the group of funding organisations referred to as 'Mixed Funders'. These POONS services were established with their own set of criteria and not those of CRMF who subsequently took over their funding. This differs to the study undertaken by Bignold et al. (1994a, 1994b, 1995a, 1995b) which described all POONSs ever funded by CRMF as PMNs.

**The Philosophies, Strategies or Ideals of Charities Funding POONSs**

Charities funding POONSs share common values in providing specialist nursing services to give the best possible care to children with cancer and their families. The way in which this has best been achieved, however, has differed greatly amongst individual organisations.

CLIC have considered the best way of achieving such aims are to work directly with DGHs, to support a local domiciliary nurse to provide total or 'direct' care (Bignold et al. 1994a) to children with malignant disease and their families. This has resulted in the nurse following the patient and family throughout the duration of treatment and beyond, either through terminal care or through the long term follow-up of surviving patients. Such care is provided to very small numbers of children, both in hospital and at home, and might include giving chemotherapy treatment both at home and in hospital, providing specialist hands-on nursing procedures as required for example, to extract blood samples from central venous access devices (CVADs) and to provide psychosocial support to the patient, siblings and family. Historically CLIC-

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4 CVADs are implanted devices which allow for frequent and/or continuous venous access. There are a variety of different types; the most commonly used for children with malignant disease is the Hickman line.
funded POONS posts established at DGHs in the SW of England, hindered the
development of more generalist PCN posts. This resulted in a two-tier service where
comprehensive nursing provision has been given to families caring for children with
cancer, whilst PCN services for children with other medical conditions have been
very limited (Tatman 1993, Whiting 1993, 1995). More recently however PCN posts
have developed alongside district-based CLIC nurses to provide PCN services to
children besides those with malignant disease.

CRMF, on the other hand, have considered the best way of achieving specialist
nursing care to families of children with malignant disease, has been through
providing MPN services based at regional specialist hospitals. Incorporated into the
strategies of early MPN posts was also a responsibility to provide specialist nursing
services to children with other life-threatening illnesses and their families (CRMF
1992). It has been suggested that they work closely with local primary and secondary
services, working in collaboration with other health care professionals (CRMF 1995),
enabling them to be the main providers of care to such families (CRMF 1992). This
has been termed ‘indirect’ care (Bignold et al. 1994a). CRMF stipulate that their
grant is dependent upon direct involvement in establishing MPN posts in the provision
of: ‘appropriate professional advice’ (CRMF 1992), in a manner similar to their adult
model of care.

With the exception of the Christian Lewis Trust (Faulkner 1994), who closely support
and model their work on CLIC by funding services at DGHs, other small charities
operating at regional centres appear to have less well defined strategies. Instead, they
often choose to raise funds for POONS posts, allowing the health care professionals
at the centres concerned to establish their own criteria. LATCH for example, fund
POONSs as part of a complete package of patient care, they suggest:

our initial intention was to help patients and parents deal with all the
pressures and difficulties of having a prolonged painful treatment so far away
from home, we rapidly had to be providers in part or whole of so much more

(LATCH 1993)
The Sunshine Trust, established specifically to fund POONSs, their travel expenses and: 'to support the cost of training programmes in childhood cancer for those nurses already working in the community' (The Sunshine Trust, undated), similarly take the advice concerning appointments of POONSs, from the regional centre concerned. The Rupert Foundation too, also worked closely with health care professionals to recognise the differing needs of individual centres.

Hence, whilst CLIC and the Christian Lewis Trust differ in their approach from the other charities involved in funding POONSs because of their local or 'district' nature, CRMF's strategy or philosophy differs from the other charities funding regionally-placed POONSs, due to their less flexible approach. Such conflicts of interest whilst being responsible for establishing differing services at different centres has also, on one occasion been responsible for the abandonment of POONS services at a regional hospital. The service originally established with funding from two different charitable organisations folded when the two charities with conflicting interests impinged on the working relationships between the POONSs providing the specialist nursing service. The POONSs subsequently left and the service re-established a couple of years later with funding sought from one single source. The author is also aware that similar mixed funding patterns are beginning to re-emerge at other centres resulting in fragmented services not only between centres but also within individual regions.

**Blurring the Boundaries between Private and Voluntary Health Care Provision**

The 'subsidized statutory' (Leat 1986) nature of the voluntary organisations associated with funding POONSs may be seen as a collaboration between the voluntary and statutory sectors. Collaboration between the two sectors, arising from the White Paper *Working for Patients* (DoH 1989a), may also be viewed as an 'income-generating' scheme by the NHS (Mohan 1991). Other such schemes include land sales, cost improvements, shopping arcades in hospitals and the 'contracting-out' of cleaning and catering services (Mohan 1991, Appleby 1992, Black 1995). This association has been increased still further by the announcement of a 'public/private' partnership to build new hospitals (Dorrell 1995, Pollock 1995). Although some health authorities have responded eagerly to such calls blurring: 'the boundaries between the two
[private and public] sectors’ (Mohan 1991:41), it would appear that in reality there has been little recent growth in the promotion of patient welfare or research through the voluntary sector (Mohan 1995). It has been estimated that such schemes only generate 0.3% of total health service expenditure. They are also seen as temporary, offering only short-term funding solutions (Mohan 1991). These problems, in relation to POONSs, have already been highlighted by the folding of both the Rupert Foundation and the POONS team jointly established by two charities with conflicting ideals, which failed. Nevertheless, such moves may be regarded as the result of ‘indirect privatization’, designed to supplement state provision resulting in the ‘reprivatization’ of health services (Mohan 1991).

The ‘reprivatization’ of health services in which the boundaries between voluntary and public sectors have become blurred, is of particular significance for health services provided to sick children. Obtaining funds to establish new, specialist nursing services such as terminal care support teams, is frequently difficult to achieve from central funding sources (Dunlop & Hockley 1990). In contrast, organisations caring for sick children have greater success in gaining financial support when compared to those with say, the elderly or mentally infirm (Brenton 1985, Mohan 1995). Nevertheless some children’s services attract greater public attention than others. This has been demonstrated in recent years not only through the funding provision of POONSs but also by the particular success of the GOS Wishing Well appeal in 1987-8 which easily exceeded its target of £25 million (Mohan 1995). GOS also calculated that 5% of its income for the period 1994/5 came from sources other than those raised through the DoH, the NHS internal market, private patients or sources provided for the training and education of doctors and nurses (GOS 1995). Successful fund raising has also been exhibited through the rapid expansion of the children’s hospice movement. Following the opening of Helen House in 1982, the first children’s hospice in the UK, public interest was such that restraint was soon urged on their further development until appropriate evaluation was conducted to determine additional needs (Stein & Woolley 1990). It is thought that the successes of childrens’ hospice appeals are grounded in the public assumption that they are built to accommodate children with cancer. In reality the majority of children cared for in hospices have chronic,
life-limiting, degenerative diseases from which families caring for them require respite care (Goldman & Baum 1994, Farrell 1996). More ‘generalist’ services such as PCN teams attract less attention, reducing the amount of financial gain from the voluntary sector (Goldman & Baum 1994).

Parallels between the blurred boundaries of public and voluntary sectors in health may also be drawn with social services, but for different reasons. The concept of ‘income-generation’ within health care is considered to be relatively new (Mohan 1991, Black 1995). The mixed economy of social services however tells a different story. Voluntary effort has been an integral part of the welfare state in providing personal social services throughout the post war period, especially in services caring for the elderly, people with disabilities and children. The mix however, has varied between services and over time (Mayo 1994). Brenton (1985) goes so far as to suggest that a mixed economy was built into the post war welfare state; core funding of social services has been described as: ‘a distinctly mixed bag’ (Webb & Wistow 1987:6).

Nevertheless, recent political moves have exacerbated this scenario. The community care policies of the 1980s focused on reducing the role of local authorities as direct service providers, thereby promoting the growth of a mixed economy. This had the effect of indirectly increasing the reliance upon the informal, voluntary and private sectors (Walker 1993:204). Boundaries between voluntary and public sectors have become blurred since the voluntary sector have been asked to fill gaps left by the withdrawal of state provision: ‘providing instead of rather than in addition to the local authority’ (Lewis 1993:179). There has been a retraction from ‘institutional’ models of care (Mayo 1994). Such models are provided as ‘first-line’ functions of modern industrial society, where the state plays a minimal, residual role:

"the 1970s and 1980s played a leading role in developing strategies for retrenchment, strategies which... were associated with attempts to shift the balance of welfare - to move towards a more residual model in general, and to promote the role of the private and voluntary sectors in particular"

(Mayo 1994:27)
A number of different and inconsistent debates have been used in favour of shifting the balance in the mixed economy of funding further towards the voluntary and private sectors (Walker 1993, Mayo 1994). Mixed economy of welfare has been considered beneficial for five reasons, including increased consumer/client choice (Mayo 1994). However such benefits are unfounded (Walker 1993, Mayo 1994). Drawing on the work of Calnan (1991) who examined 3000 middle-aged men living in Kent receiving private health insurance, Mayo concluded that since most received this as a fringe benefit or a managerial perk of their employment and did not know which was the best buy, relying on their GPs for information, consumer choice was limited.

The increasing number of private nursing homes have also been questioned in relation to consumer choice (Walker 1993). A switch in the provision of residential care from the public sector to the private sector was encouraged and increased following the NHS and Community Care Act (1990). However choice in nursing homes is seldom possible. The elderly are often restricted by their ability to pay, waiting lists and geographical location; furthermore choice may be hampered within given areas, by the admission criteria of private homes which may exclude the confused or demented, or those difficult to control.

In summary, this section of the chapter has suggested that policies of the 1980s and 1990s have encouraged increased reliance upon the voluntary sector. Analogies have been drawn between health and social services to suggest that whilst reliance upon the voluntary sector was ‘built into’ the construction of the welfare state in social services, ‘income generation’ in health care is relatively new. Such moves have ‘blurred the boundaries’ between the two sectors. Whilst it remains difficult for some sections of the community to attract voluntary donations, certain children’s services such as those associated with POONSs, are particularly popular with the general public. Thus the boundaries between the public and voluntary sectors, in relation to services for children with cancer are particularly blurred. Client choice, purported as a benefit of mixed economy, is largely rhetorical. Client choice, in relation to POONS services will be discussed later in this thesis.
Conclusion

This chapter has addressed the mixed economy of health care; more specifically it has dealt with 'income generation' by the NHS, through the voluntary sector. An historical review has highlighted the important role of the voluntary sector in establishing health care services, more particularly in nursing. A return to increased dependence on the voluntary sector has been highlighted through the social services. It has also been illustrated through the ease with which some paediatric services enable this to occur. The charitable organisations associated with POONSs were highlighted as such an example and the problems for nurses, associated with divergent strategies adopted by charities, alluded to. In discussing the role of the voluntary sector both in social services and health, it has been suggested firstly that boundaries between public and voluntary sectors have become increasingly blurred and secondly that choice within a market-driven economy, is largely rhetorical.

Little has been learnt from history. In spite of the rationale behind the NHS, during the mid 1990s government policy has looked to increase the voluntary sector input into health care, returning to a fragmented and complex system. The 'subsidized statutory' nature of voluntary organisations (Leat 1986) associated with POONSs provides a means of income-generation; the charities assist in the process of moving health care towards 'reprivatization' (Mohan 1991) or a 'residual' model of health care provision (Higgins 1986), thereby learning little from the experiences of the past.

In the light of current health policies and the potential increase in voluntary sector funding within the NHS, the impact that varying strategies adopted by charities has upon health care professionals cannot be underestimated. In particular this research seeks to address the impact of such strategies on the relationships between health care professionals; the relationships between POONSs and their colleagues is the overarching theme to this research and will be developed further in the ensuing chapters.
Chapter Four - Professional Relationships in Health Care: 
A Review

Introduction

The central theme of this research is to examine the impact of different funding arrangements of POONSs on their professional relationships. A particular focus will be to explore whether opposing strategies adopted by the main charities identified with funding their work, are associated with varying levels of knowledge and whether, in turn, such differences impact on relationships formed with other health care professionals. This chapter therefore sets the scene from three main perspectives: firstly sociology of the professions will briefly be discussed in order to site the importance that a body of knowledge plays in gaining professional status. In so doing, in relation to this study, the limitations of current theoretical arguments pertaining to the importance of a body of knowledge for achieving professional status will be highlighted. Secondly a discussion of both the professional relationships between nurses and doctors and between nurses themselves will be presented. This discussion will determine firstly that the current understanding of relationships between different groups of hospital-based nurses is extremely limited and secondly, that relationships between doctors and nurses (particularly when they are highly specialised and experienced) are similarly under studied in the light of the many recent changes which have occurred in the British health care system.

Finally, a discussion on both 'empowerment' and 'partnership' is presented. Here it is argued that, during the late 1990s, it is insufficient merely to talk of professional relationships between health care professionals. Instead such concepts, which currently hold much favour with professionals and policy makers alike, need be employed to examine the ways in which close professional relationships may be achieved. Both 'empowerment' and 'partnership' will be discussed to suggest that whilst much lip service is currently payed to these concepts, little empirical work has been undertaken to qualify the rhetoric.
The 'Profession' of Nursing

'Professionalization' may be regarded as: 'the process by which an occupation develops the characteristics of a profession' (Hamilton 1992:32) and in which a 'power struggle on a societal level' (Larson 1977:157) exists. This process has also been referred to as a 'professional project' (e.g. Larson 1977, Walby et al.1994, Macdonald 1995). Whilst medicine, the law, the clergy, architecture, accountancy and dentistry have all been regarded as traditional occupations which have attained professional status (e.g. Illich et al. 1977, Larson 1977, Freidson 1970 & 1986, Dingwall & Lewis 1983, Abbott 1988, Abbott & Wallace 1990a, Nettleton 1992, Macdonald 1995), with few recent exceptions (e.g. Keogh 1997), nursing has more usually been dismissed as a profession. Instead nursing is more commonly viewed as a 'semi-profession' (Etzioni 1969) or one of the 'caring' professions (Abbott & Wallace 1990a, 1990b).

With the exception of 'traditional' professions, industrialisation brought confusion in defining professional status - increased educational opportunities arose which led to the expansion of professionalization amongst the emerging middle classes (Johnson 1972, Larson 1977). Nevertheless there have been theorists who have attempted to define the concept of a 'profession'. The result has been, though, little current agreement amongst sociologists as to the meaning of profession (Porter 1992), leading Dingwall (1977:118) to suggest: 'that a profession is nothing more or less than what some sociologist says it is!'.

In spite of nursing's attempts to professionalize over recent years (Porter 1992, Keogh 1997) nursing is still generally not regarded as a profession (e.g. Etzioni 1969, Abbott & Wallace 1990a, Lorentzon 1990, Macdonald 1995) due to its lack of professional attributes. 'Trait' theory, popular amongst functionalist sociologists in the 1950s and 1960s (for example Parsons 1954, Goode 1957, Marshall 1963, Etzioni 1969) suggested that to achieve professional status a number of characteristics or 'traits' of an ideal professional type need be attained. One of the major traits assumed to be required to achieve professional status has been that of a specialist body of knowledge. Nursing, according to trait theory, does not achieve a professional
position since graduate status, a prerequisite for achieving the title of 'profession' is not necessary to enter nursing. Since trait theory, the educational status of nursing has continued to blight nursing's claim to professional status with entry into nursing via more than one access route (i.e. through degree courses and diploma courses) continuing to be seen as problematic (e.g. Hamric 1992, Adams 1996).

Larson's (1977) early contributions to the debate on professions noted that large discrepancies of status and rewards existed within professional communities. However when touching upon the discrepancies within any given profession, she fails to address that variance in status and rewards are grounded in differing levels of knowledge gained from experience. More recently, questioning the relation between gender and profession, Davies (1996) has acknowledged that specialists within a profession are more highly regarded than generalists. However she does not take this point further to give any indication of who are regarded as specialists and by whom they are more highly regarded compared to generalists. Such statements therefore fail to address whether nurses specialising in a particular field with which doctors are unfamiliar may be highly regarded by more generalist doctors - a question which this research attempts to address.

Trait theory has more recently been criticised for its over simplification (e.g. Dingwall & Lewis 1983:6-12, Abbott & Wallace 1990a, Porter 1992, Witz 1992, Macdonald 1995). Nevertheless ever since the postulation of trait theory nursing has been regarded by sociologists as a semi-profession: the lack of a specific body of professional knowledge has been held responsible for hindering the course of professionalization. Despite the criticisms of the trait theory approach, there has been a major assumption in trait theory and subsequent theories which appears to have remained unchallenged. Namely that professions such as medicine, the clergy and the law (often still regarded as 'true' professions) which attain professional status through the acquisition of a body of knowledge specific to their particular trade, are then treated by sociologists as an homogenous professional group. Taking professional knowledge as a key factor to achieving professional status, no account is taken either of professional experience or of the effects of intraprofessional specialisation. In other
words once basic professional requirements to practice within a profession have been attained any further attempts in defining professional knowledge stops. This study sets out to challenge existing theories within the sociology of the professions and to examine the importance of both experience and intraprofessional specialisation in the process of gaining professional knowledge, and subsequent professional status.

**Professional Knowledge: Education and Experience**

_Even the youngest doctor must have a great deal more knowledge about diseases and about remedies than almost any nurse can have.... the experience, too, of even a young doctor is in reality larger than that of an old nurse; he has seen a great many cases in the hospital when a student, and studying them with the advantages of his superior knowledge must have learned more about each than a nurse possibly can have done_  

(West 1854:18-19)

As discussed above, the acquisition of specialist knowledge has in the past, as well as presently, been a hook on which debates within the sociology of the professions have been hung. Indeed professions have been described as: 'occupations based on advanced, or complex, or esoteric or arcane knowledge' (Macdonald 1995:1). Professional knowledge has been a focal point within the theorising of professions since 'trait' theory - functionalist sociologists have argued that professional knowledge has great social value which economically benefits society (e.g. Macdonald 1995). The possession of specialist knowledge has featured as a characteristic which distinguishes one profession from another; it has also contributed towards professionals’ power over society (e.g. Hugman 1991). Macdonald (1995) has built on Weber’s (1978) arguments that knowledge is explicit through being ‘certified and credentialed’, suggesting that such credentials are grounded in high level qualifications, typically through gaining a degree. The acquisition of professional knowledge has further been grounded within science and technology; it has underpinned the development of professional autonomy.
Each of these perspectives examines the significance of knowledge within the professional debate; whilst ‘trait’ theory has been dismissed by more recent sociologists for an over simplistic approach. There has been limited recognition of specialities within professions, with authors preferring to talk of specialist knowledge as that which distinguishes one profession from another, viewing professionals as homogenous groups. Within these groups the acquisition of a professional body of knowledge continues to be viewed from the baseline perspective, ignoring the importance of continued learning and the part that experience plays in continuing to develop professional knowledge. Although recent authors (e.g. Keogh 1997) have argued that university education is rapidly professionalising nursing, others have argued that nursing’s claim to achieving professional status continues to be hampered by a lack of statutory high level (i.e. degree level) qualification.

Professional knowledge has often been referred to as pertaining to a speciality e.g. medical knowledge, nursing knowledge and makes the assumption that an acquired body of knowledge belongs to a particular profession, separating one from another (e.g. Beattie 1995). Beattie (1995) for example discusses socio-anthropological insights into the differences between medicine and nursing in terms of: ‘specialist professional training schools’ (Beattie 1995:14), whilst Mackay (1993) has proposed that greater numbers of students enter medicine than nursing for the ‘scientific’ element. In contrast to sociology of the professions, nursing literature has recognised the importance that formal education plays in marking the beginning of learning their profession (e.g. MacLeod 1996) and the role of experience in becoming expert (Benner 1984). Both of these components of ‘professional knowledge’ will be discussed in more detail below in relation to the CNS.

Knowledge and the Clinical Nurse Specialist
A major problem for CNS positions has always been the lack of a common definition of the role (see Chapter Two). This lack of definition, argues Hamric (1992), has more recently been compounded by a poor understanding of the differences between the CNS and the ANP since both are defined as ‘expert’ through the gaining of ‘experience’. Gaining experience, and its role in becoming ‘expert’, was first
described by Benner (1984) and has more recently been re-examined through the work of MacLeod (1996). Confusion between the CNS and ANP roles, argues Hamric, gives rise to the assumption that nursing’s full professional role is achievable through registration and years of clinical experience. Whilst nursing systems in the UK differ to those in the USA, some parallels may be drawn in that a dichotomy exists between the importance of professional qualifications on the one hand and professional experience on the other. Hamric’s criticism of Benner seems to imply that professional experience cannot match the benefit of professional training when achieving advanced status, whilst MacLeod (1996), like Benner, highlights the importance of gaining experience from ‘on the job’ learning. Hence, whilst there are differences of opinion as to whether professional education or professional experience best constitute professional ‘nursing’ knowledge in relation to CNSs, both have been recognised as important in achieving ‘expert’ status.

In relation to CNSs working in cancer care in the USA, the acquisition of knowledge and skills have been described as of lesser importance to health care professionals working with them than personalities (see Chapter Two - Personalities of CNSs) (McGee et al. 1987). Nonetheless within this study distinctions are drawn between ‘knowledge’ and ‘skills’. Since a total of 363 competencies were categorised in McGee et al.’s study these are somewhat difficult to disentangle. However it would appear that ‘knowledge’ competencies of the CNS include that which makes up the direct care provision, the consultative role, the manager role, researcher and educator. Whilst ‘skills’ are required for the role of nurse consultant, direct care provider, educator, manager and researcher. How these are distinguished however, remain unclear. This study contrasts with the work of Cox et al. (1993) which employed the critical incident technique to examine the work of a Macmillan nurse. Here both patients and professional carers alike greatly valued the nurse’s specialist knowledge of terminal cancer care.
Nursing has been described as both an art and a science (for examples see Kitson 1993, Lipman & Deatrick 1994). The 'science' part of nursing has been described as that which concerns the acquisition of knowledge which enables nurses in the process of clinical decision-making, whilst the 'art' of decision-making uses the experiences of nurses and others around them: 'to collaboratively assess [patients] and formulate appropriate interventions' (Lipman & Deatrick 1994:55). Nonetheless, it is argued that both the 'art' and the 'science' of clinical decision-making are enhanced through educational programs established for CNSs in two ways; firstly, CNS curricula can enhance learning to minimise sources of uncertainty which are under the control of the CNS and secondly educational programs enable CNSs to acquire the types of knowledge necessary for clinical decision-making (Lipman & Deatrick 1994). Although no such curricula currently exist in the UK, the second approach to acquiring specialist knowledge is of particular relevance to British CNSs. Quoting Diers (1985), Lipman & Deatrick suggest that there are three types of knowledge required by CNSs in order that they can make clinical decisions:

(1) **Clinical judgement** which begins with a strong science base and differs according to specialty. This knowledge base forms the foundations for skills in physical, developmental and psychosocial support. Here, factual knowledge gleaned through patient assessment must be applied inductively to formulate a decision.

(2) **Scholarly Inquiry** which is essential for clinical decision making which becomes integrated into the inductive process. These skills are learned through knowledge of research design and scholarly inquiry. Clinical nurse specialists will question clinical practice, investigate alternatives and seek consultation when making decisions.

(3) **Leadership** is necessary for decision-making based on health policy. These policies demonstrate where money, power and history lie which increase the effectiveness of the CNSs decision making in clinical situations.
Hence, what this section has suggested is that whilst some authors propose that expertise primarily comes from experience, others have placed greater or equal importance upon professional training when discussing nurses' knowledge.

General practitioners, community nurses and hospital consultants lack knowledge concerning the needs of adults dying at home from cancer (e.g. Cartwright 1991, Schaerer 1993, Lopez de Maturana et al. 1993, Wakefield 1993). This lack of knowledge along with the very few children who die at home from cancer (see Chapter Two) suggests an even greater lack of knowledge concerning the needs of children with cancer and their families. Hence the importance and meaning of professional knowledge to those health care professionals working with POONSs, will be examined during the course of this study.

In summary, whilst current theories in the sociology of the professions, ignore the importance of experience and intraprofessional specialisation in defining professional status, nursing literature places great emphasis upon expertise gained not only through professional training but also through experience. However in relation to CNS roles, emphasis in some studies has also been placed upon personalities. In relation to the work of POONSs this study seeks to address the effects of mixed funding sources upon the balance between professional education, experience and individuals' personalities and the importance these components have upon relationships developed with other health care professionals. In order to address these questions it is first important through reviewing the current literature, to gain an understanding of the relationships between nurses and those who they work closely with. This will be undertaken in the following sections which will firstly examine interprofessional relationships and secondly, intraprofessional relationships.

**Interprofessional Relationships**

The study of interprofessional relationships has developed from a need to better understand the workings of large organisations and more recently, also, the workings of small semi-autonomous units. Changes in interagency work have also been brought about through the implementation of the NHS and Community Care Act 1990 which
has required greater numbers of health, social care and members of the voluntary sector to share concerns for the well-being of patients/clients (Hallett & Birchall 1992, Walby et al. 1994, Dockrell & Wilson 1995, Hugman 1995). In recent years there has been a surge of interest in interprofessional relationships in health care in the sociological, medical and nursing literature (e.g. see Mackay 1993, Ajemian 1994, Walby et al. 1994, Porter 1995, Soothill et al. 1995, Sweet & Norman 1995). This interest has arisen through concerns from both within and outside the health care system (Mackay et al. 1995). Moreover good working relationships are considered by both doctors and nurses to be of paramount importance to patient care (Mackay 1993, Hansen 1995). Furthermore changes in NHS management, which arose from the White Paper Working for Patients (DoH 1989a) and which led to devolving authority closer to wards and clinics through clinical directorates, has meant that: 'a health care service [is provided] together, not just at an occasional interprofessional liaison committee, but day-to-day in clinics, surgeries and hospitals' (Walby et al. 1994:17). Of particular note, those concerned with palliative care services have suggested that the study of working relationships within the specialty arose as a consequence of exploring stressful situations amongst professionals (Herxheimer et al. 1985, Ajemian 1994).

The notion of interprofessional work may encompass a number of overlapping terms including teamwork, interprofessional, collaboration and collegiality (Hansen 1995, Ross & Mackenzie 1996). Therefore, within the context of this study the concept of 'interprofessional' will be used to refer to the relationships between doctors and nurses. 'Intraprofessional' will examine the relationships between groups of nurses.

**Interprofessional Relationships - The Doctor-Nurse Relationship**

*Working 'interprofessionally' means crossing occupational boundaries, setting aside the 'rightness' of our own view of health care and having a willingness to listen to what colleagues from another profession are saying*

(Mackay et al. 1995:5)
It was originally the intention of this study to explore professional relationships between POONSs and other health care professionals with whom they closely work (including medical social workers). There has been an increasing body of empirical literature on interprofessional relationships between differing groups of health and social care professionals and their managers (e.g. Larkin 1978, Curtis 1994, Chapman et al. 1995, Dockrell & Wilson 1995, Harding & Taylor 1995, Hugman 1995). In spite of the wealth of data collected during the course of this study, analysis has focused on interprofessional relationships between POONSs and doctors because emerging relationship types between POONSs and their medical colleagues differed to those reported in the literature. Hence the nurse-doctor relationship will be the focus of this section of the chapter.

Whilst the importance to patient care of other health care professionals and ancillary staff has been acknowledged (e.g. Mackay 1993, Walby et al. 1994, Mackay et al. 1995), there is much agreement that the professional relationship between nurses and doctors working within a hospital environment is an especially important one, due to the frequency with which they need to communicate concerning patients' well-being (for example see Stein 1978, Mackay 1993, Walby et al. 1994, Porter 1995). It has also been argued that acute hospitals are the environment in which most health professionals begin their careers and thus absorb ideas about professional relationships (Mackay 1993, Walby et al. 1994). However, recent reviews of the literature on the doctor-nurse relationship suggest that empirical studies on the subject are somewhat scanty (Porter 1995, Sweet & Norman 1995). The aim of the following sections will be to review this limited body of literature from an historical perspective, discussing inequalities in power between doctors and nurses, traditional and stereotypical views about doctors and nurses and highlighting some recent moves which have resulted in changing relationships between doctors and nurses.
The 'Doctor-Nurse Game'

The 'doctor-nurse game' first described by Stein (1967), is the seminal work on which subsequent explorations of the doctor-nurse relationship have been grounded (for example see Stein 1978, Stein et al. 1990, Mackay 1995, Porter 1995, Sweet & Norman 1995, Svensson 1996). More recently this 'game' has been referred to as a relationship in which 'informal covert decision-making' behaviour is exhibited by nurses (Porter 1991, 1995). The 'doctor-nurse game' refers to the rules which reign over the interactions between doctors and nurses in which an intricate game is played, where decisions are covertly made by nurses and are taken up by doctors who give the appearance of having made such decisions themselves:

> the nurse is to be bold, have initiative, and be responsible for making significant recommendations, whilst at the same time she must appear passive. This must be done in such a manner so as to make her recommendations appear to be initiated by the physician (Stein 1978:109)

Sweet & Norman (1995) have argued that Stein's description of the 'doctor-nurse game' has remained a popular theory on which to build, since it strikes a familiar chord with members of both professions. Building on this theory, this chapter will establish how relationships between doctors and nurses have evolved since the 'doctor-nurse game' was first described.

**Historical Perspectives**

In studying the relationships between doctors and nurses who worked or trained in Canada during the 1920s and 1930s, Keddy et al. (1986) suggested that the 'doctor-nurse game' was engaged in during this period. However re-examining the work of Keddy et al. at a later date, along with historical work by Darbyshire (1987), Porter (1995) concluded that up to and during the first quarter of this century, nurses had an almost totally subservient relationship with doctors. Porter suggests that the nurses interviewed in Keddy et al.'s study were unable to implement the 'doctor-nurse game' since they were powerless to contribute to the decision making processes, sometimes resorting to going behind doctors' backs.
Subservience is certainly evident in the relationship between doctors and nurses during the mid part of the last century, through the writings of Charles West, the founder of GOS. Writing in a text book for nurses undertaking sick children’s nursing, he suggests that the nurse must not interfere with a doctor’s instructions or be allowed to have ideas of her own. Indeed he goes so far as to state that a nurse meddling in the decisions made by doctors may bring about the demise of a child:

*the nurse is not the doctor....she never can be...if she forgets her proper place, and tries to interfere with his duties, or to set herself above his directions, instead of being a blessing she will be a curse, instead of promoting the child’s recovery she will very often hasten its death*  
(West 1854:16)

It is uncertain what nurses themselves felt about such attitudes but Porter (1995) makes the point that nurses strove to achieve the Nurse Registration Act of 1919 in an attempt to gain a more equal status with doctors, seeking to reduce their subservience to them. Between the 1930s and the 1960s there were strong indications that nurse-doctor relationships gradually shed some of their authoritarian characteristics, in which the ‘doctor-nurse game’ can be seen as part of this process (Porter 1995). Porter suggests that this period of time:

*stands as an intermediate stage between the total absence of nursing rights to participate in decision-making, and the right to openly voice recommendations*  
(Porter 1995:41)

From the 1960s onwards, following the publication of Stein’s work, the ‘doctor-nurse game’ is in evidence (Porter 1995). Although there is little doubt that relationships between doctors and nurses have become more egalitarian during the last two decades (e.g. Hughes 1987, Stein et al. 1990, Walby et al. 1994, Porter 1995, Hunt 1996, Svensson 1996), there is some evidence to suggest that in certain quarters, such relationships still exist. Some of the underlying, contributory factors relating to the ‘doctor-nurse game’ are therefore highlighted below.
Power, Patriarchy and Stereotyping - Traditional Nurse-Doctor Relationships

Put simply: 'Patriarchy is the exercise of power by men over women' (Hugman 1991:190). It has often been considered by sociologists that medicine has been dominated by men whilst nursing work has traditionally been undertaken by women. This has frequently given rise to gender inequalities explaining the imbalance in professional status and power between medicine and nursing (e.g. Abbott & Wallace 1990a & 1990b, Hugman 1991, Witz 1992, Walby et al. 1994, Carrier & Kendall 1995, Kendrick 1995, Sweet & Norman 1996). Because inequalities in power exist, patriarchy ensues (Hugman 1991, Witz 1992, Porter 1995). In parallel, traditional views of relationships between health care professionals have seen nurses in ‘caring’, feminine semi-professional roles, whilst doctors roles are ‘curative’, masculine and professional (e.g. Dingwall & MacIntosh 1978, Jecker & Self 1991, Walby et al. 1994, Kendrick 1995, Sweet & Norman 1996). These ‘traditionalist’ views have been portrayed and enhanced through television media and novels, commonly casting women as nurses and men as doctors (Stein 1978, Kalisch & Kalisch 1984). They are further reinforced and perpetuated by medical and nursing students who depict elements of role stereotyping when highlighting reasons given for entering their chosen profession (Mackay 1993). However, it has been suggested that passive, feminine traits such as caring and active masculine ones such as curing, are processes which are learnt through socialization rather than being inherent (Sweet & Norman 1996). This, it is argued: 'paves the way for nurses to assume a more proactive role in relationships with their medical colleagues' (Sweet & Norman 1996:167) and may contribute towards the existence of a less patriarchal relationship. Hence interprofessional work in health care may currently be viewed as: 'the redistribution of power' (Mackay et al. 1995:8) from doctors to others with whom they work, including nurses.

Although there is increasing evidence to suggest that traditional patriarchal, power relationships between certain groups of doctors and nurses are eroding (for example see Hughes 1987, Mackay 1993, Svennson 1996, Hunt 1996), recent studies suggest that patriarchal relationships between doctors and nurses still exist (Mackay 1993, Porter 1991, 1995, Walby et al. 1994). Such relationships however, are limited and
usually restricted to professional relationships between junior nursing staff who lack confidence to make decisions and more traditionalist senior medical staff (Walby et al. 1994, Porter 1995); relationships between more experienced nurses and junior doctors may be less patriarchal as experienced nurses challenge the decisions made by junior doctors (Walby et al. 1994). In other settings patriarchy has diminished still further so that the 'interplay' between all levels of doctors and nurses ensues in 'negotiation' between the two professional groups (Svennson 1996); little distinction is made by them between the work of doctors and that of nurses (Dunlop & Hockley 1990:45-46). Nonetheless, doctors have retained a more dominant position over nurses since they maintain authority over admitting patients to hospital. They also make decisions about treatment and discharge of patients and, despite recent moves by the UKCC to make nurses more accountable for their actions (UKCC 1992b), it is still argued that doctors hold final and legal responsibilities for patients (Walby et al. 1994, Boosfeld 1995, Mackay et al. 1995).

The inequalities in power and the patriarchal relationship which has existed between doctors and nurses help explain the 'doctor-nurse game'. The erosion of such powers and patriarchy similarly assist in understanding the gradual decline in the presence of the 'doctor-nurse game', which has resulted in a more generalised 'informal overt decision-making' relationship (Porter 1991, 1995) (discussed in more detail below).

Eroding the Stereotypes - Men in Nursing and Women in Medicine

Although patterns are changing, the majority of senior and/or managerial positions in both nursing and medicine are still held by men (for example see Hugman 1991, Mackay 1993, DoH 1995b, Snell 1996). Compounding this, the numbers of men entering nursing appear static, at between 3 - 10% of the nursing workforce (Hugman 1991). Nonetheless with 50% of students entering the medical profession being female1 (Mackay 1993, Walby et al. 1994), and men in nursing sometimes assuming

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1 The equal numbers of men and women entering medicine reduce with greater seniority. However certain specialties attract higher numbers of women and include areas in which POONSs work closely with doctors (paediatrics and general practice). 30% of practising GPs are women (DoH 1995b).
a more equal role with doctors (Mackay 1993), the traditional stereotyping of 'masculine' medical and 'feminine' nursing roles appear to be eroding.

The Disintegration of the 'Doctor-Nurse Game'

Recent studies continue to describe instances of 'unmitigated subordination' between nurses and doctors (Porter 1995) and have suggested that nurses continue to maintain an acceptance of authority from consultants (Mackay 1993, Walby et al. 1994). Nonetheless, it has been acknowledged since the late 1970s that relationships between doctors and nurses have become less subservient; the 'doctor-nurse game' is less apparent (Hughes 1987, Stein et al. 1990) and traditional boundaries between the two occupational groups are becoming increasingly grey (e.g. Walby et al. 1994, Dowling, Barrell & West 1995, Beattie 1995, Mackay et al. 1995, Dowling 1997).

A qualitative examination of the relationships between nurses and doctors in a casualty department during the late 1970s suggested that nurses did not always feel compelled to play the 'doctor-nurse game' (Hughes 1987). A decade later a similar more overt relationship between doctors and nurses was described in an Intensive Care Unit (ITU) in Northern Ireland which has been referred to as: 'informal overt decision-making' (Porter 1991, 1995). Greater use of the 'informal overt decision-making' model has resulted in dialogue between doctors and nurses which has challenged previously unquestioned power held by doctors (Porter 1995).

How far interprofessional relationships between nurses and doctors have moved away from subservient, patriarchal or 'informal covert decision-making' models to a more collegial, egalitarian relationship where decisions about patient care are made overtly by nurses, is not only dependent on the levels of seniority of both doctors and nurses. Attitudes are also dependent upon work location: traditional nurse-doctor relationships are more likely to prevail in provincial hospitals rather than in specialist or teaching hospitals (Mackay 1993, Porter 1995). In addition relationships are influenced by medical specialties. However findings from different studies have produced conflicting opinions regarding the doctor-nurse relationship within the same speciality, particularly within ITU (Mackay 1993, Walby et al. 1994). Furthermore,
relationships between doctors and nurses are influenced by the nature of ‘tasks’. Whilst some contested ‘tasks’ have caused friction between the two groups of health professionals, particular clinical areas such as palliative care and ITU, have been responsible for enhancing working relationships between nurses and doctors (Mackay 1993, Walby et al. 1994).

Mackay (1993) has suggested that the use of the ‘medical’ model of care by nurses in specialties such as ITU where there is much contact between medical and nursing staff, does much to establish a good rapport between doctors and nurses. Similarly she suggests that there is a shared intimacy between doctors and nurses working in the operating theatre. This intimacy is enhanced by the geographical location of the operating theatre which is frequently isolated from the rest of the hospital. In contrast, Walby et al. (1994) have suggested that in areas of the hospital where doctors and nurses work together in close proximity, such as ITU, terminal care and wound healing, relationships between doctors and nurses are particularly strained. Such relationships, they suggest, are the result of contested areas of work where professional overlap exists, often resulting in conflict.

Of poignancy to this study, relationships between nurses and doctors on the paediatric unit are noted by their friendliness and informality, to be different compared to relationships between doctors and nurses in other units. A brighter atmosphere prevails in which first names are usual (Mackay 1993:27-31). Also, traditional professional boundaries between doctors and nurses working in hospices are lacking since hospices are: ‘separate from the mainstream health care and are comfortable places to work’ (Herring et al. 1995:55).

In summary, patriarchal relationships between nurses and doctors continued through to the late 1980s although there is much evidence to suggest that nurses are currently more likely to participate in open discussion with doctors, regarding patient management. However this is much more evident with experienced nurses, those working in teaching hospitals and in certain specialities. Particularly friendly and informal relationships between nursing and medical staff working in paediatrics have
been noted through the qualitative work of Mackay (1993) and a more egalitarian relationship has been observed in hospices, away from the more formal hospital environment (Herring et al. 1995) and specialist teaching hospitals.

The Changing Doctor-Nurse Relationship

The last two decades have been a period of rapid change for health care provision in the UK. Advances within both the medical and nursing professions and changes in the managerial structure of the NHS, brought about through government policy, have contributed to the transformation of professional relationships between doctors and nurses. Such transformations have arguably, succeeded in contributing towards the further reduction of medicine’s power over nursing and has invariably led to reduced clarity between nursing and doctoring roles. Four recent major developments which have contributed to such changes are briefly highlighted below.

(1) Changes in health policy and the management of care:

Reforms in health care which have stemmed from the White Paper Working for Patients (DoH 1989a), have brought about great changes in the managerial structure of the NHS. Furthermore, such initiatives have encouraged hospital consultants to pursue managerial roles (e.g. Lorbiecki 1995). Whilst some senior doctors have acted upon this encouragement (Lorbiecki 1995, Brown & McCartney 1997), for others it has meant that power has been devolved away from them, towards the professional manager (Mackay et al. 1995). This has meant that health care professionals - doctors and nurses alike - may have: ‘more in common than they thought’ (Mackay et al. 1995:10), with doctors and nurses working together for the good of patients whilst managers control budgets. In parallel, ‘new wave management’ encourages bypassing of traditional professional hierarchies and devolves power and accountability to ward and clinical directorate level (Walby et al.1994). Devolving power to this level encourages collaboration and interdisciplinary teamwork which requires leadership; who provides this leadership however, may be contested (Walby et al. 1994). Hence whilst new management structures may encourage a more collegial approach to interprofessional relationships between medical and nursing staff, uniting to create barriers between themselves (‘the professionals’) and their managers, professional
boundaries over leadership may be contested. This may result in a struggle for power between nursing and medicine, contributing to a lack of clarity between the boundaries of the two professions.

Strategic changes in thinking vis-à-vis interventions in health care are also responsible for diminishing boundaries between medicine and nursing. Taking an anthropological viewpoint, Beattie (1995) for example, highlights four contrasting models of 'practice paradigms' which differ in their approach, with each finding favour amongst different groups of health care professionals (Beattie 1995). Such preferences may cut across traditional 'tribal boundaries' of individual subspecialties. The first two 'practice paradigm' models: the Biotechnological model and the Biographical model in particular may have implications for the relationships developed between POONSs and other health care professionals. Without the support of POONSs, community-based health care professionals and local hospital staff lack the knowledge to provide for the 'Biotechnological' model of health care for the child with cancer, which focuses on rectifying 'mechanical' defects. This allows POONSs to cross doctor-nurse boundaries, providing information to GPs and consultant paediatricians to enable them to participate in the 'Biotechnological' model. Secondly, hospital-based doctors may be less interested than POONSs and PHCTs in the day-to-day well-being of patients and therefore less concerned with components of the 'Biographical' model, which focuses on troublesome life events. In this instance POONSs' and GPs' professional interests alike cross doctor-nurse boundaries since they may share mutual concerns. Similarly holistic approaches to both general practice and nursing have recently been born out through the work of May & Fleming (1997).

What the above two points have illustrated is that there are not only changes within health care policy which have affected the changing relationships between nurses and doctors, but that cultural changes affecting the way health care is delivered have also contributed towards differing relationships between doctors and nurses.
The Nursing Process and Project 2000:

Both the Nursing Process and Project 2000 may be incorporated into what has been termed: ‘The New Nursing’ (Wainwright 1994, Walby et al. 1994). ‘The New Nursing’ is a term which encapsulates many of the events which have occurred during the last 20-30 years and which have mounted a strong challenge to the traditional views of nursing and the doctor-nurse relationship.

The nursing process may be defined as: ‘a logical systematic approach to nursing care which ensures that the nurse has the information she requires to plan and implement care planning..... which determines the care needed by a patient whatever his diagnosis and the care setting in which he is nursed’ (Hunt 1978:82).

It has been argued that the theory behind the nursing process has significance for the changing doctor-nurse relationship (e.g. Mackay 1993, Porter 1995); it questions the prerogative of doctors to claim ownership of diagnosis and subsequent prescription:

This claim to a diagnostic role for nurses goes to the heart of medical dominance, because one of the fundamental bases of that dominance is doctor’s control over diagnosis (Porter 1995:42)

Although empirical data is lacking to support this supposition, it is said that ‘formal decision-making’ responsibilities on the part of nurses, associated with the Nursing Process, has little impact upon their positions of power with doctors (Porter 1995).

Project 2000 was the initiative of the UKCC (1986). It has been associated with giving nurses a greater sense of responsibility and autonomy through attaining higher levels of education (e.g. Kendrick 1995). There is general agreement that Project 2000 moves the nurse-doctor relationship along a pathway of closer integration (e.g. Beatty 1995, Porter 1995, Walby et al. 1994). However whilst the ethos of nursing may be changing, the degree of structural entrenchment that nurses are faced with, makes the prospects of radical change seem remote (Walby et al. 1994). Furthermore there is evidence to suggest that doctors fail to support the notion of their roles being eroded through the implementation of Project 2000 (Walby et al. 1994, Porter 1995).
(3) Interprofessional Education:
An integrated approach to interprofessional education has been encouraged both internationally since the publication of *Learning Together to Work Together for Health* (WHO 1988) and nationally since the dawn of Project 2000 (UKCC 1986) in which it was envisaged that:

*New ideas and new structures ...... could form the basis for a common foundation for shared learning with other health workers. This could be a step on the road to common foundation programmes for all health workers and to health manpower development along the lines envisaged by the WHO* (UKCC 1986:47).

Since this time there has been much debate about interprofessional educational initiatives (e.g. Horder 1992, Leiba 1993, Carpenter 1995, Beattie 1995). In particular, Beattie (1995) suggests that the implementation of Project 2000 has assisted towards a more integrated learning approach which does much to transcend the ‘tribalism’ of health professionals. Joint educational initiatives at postgraduate level currently exist, such as the multidisciplinary MSc. courses which run at the Royal Marsden Hospital. While one early evaluation of interdisciplinary undergraduate study for medical and nursing students appears favourable (Carpenter 1995) others appear less so (see Horder 1992); the impact of interprofessional education on the doctor-nurse relationship requires greater analysis before conclusions can be drawn.

(4) The Advanced Nurse Practitioner Role and Reduced Doctors Hours:
Further recent initiatives which add to the lack of clarity between doctoring and nursing and which have begun to confuse the doctor-nurse relationship still further during the 1990s, concern the development of the Advanced (or Specialist) Nurse Practitioner (ANP) and reduced doctors hours.
It has long been recognised that during a shortage of doctors, nurses have filled gaps and undertaken doctoring roles. As long ago as 1870 'Sister Dora', famous for her nursing treatment of 'machinery accident' victims, was taught by Dr. MacLachlan the senior surgeon of Walsall Cottage Hospital, to perform operations such as suturing, splinting fractures, finger amputation and tracheotomy (Manton 1971). Such tasks were undertaken by her since the necessary voluntary donations to run the hospital were limited and the hospital could not afford to employ a junior house surgeon.

Much uncertainty surrounds the nature, purpose and definition of the ANP role (e.g. Castledine et al. 1996, Lorentzon & Hooker 1996, McGee et al. 1996). Over recent years the role has progressed, firstly from The Extending the Role of the Nurse document (DHSS 1989) and latterly The Scope of Professional Practice document (UKCC 1992a), both of which encourage nurses to expand their practice. Nurses themselves commonly consider that the ANP role enhances the role of the nurse (e.g. Castledine 1994, Castledine 1996, Mills 1996, Deacy & Smith 1997). Others (e.g. Dowling, Barrett & West 1995, Cassidy 1996, Dowling et al. 1996, Dowling 1997) however have viewed the ANP role as replacing junior doctors much as 'Sister Dora' did over 100 years ago: a view which has been enhanced through political ideology:

Local managers, in consultation with their professional colleagues, will be expected to re-examine all areas of work to identify the most cost-effective use of professional skills.....Examples include the extended role of nurses to cover specific duties normally undertaken by junior doctors in areas of high technology care and in casualty departments (DoH 1989a:15)

Whilst advancing nursing practice and dissolving the boundaries between medical and nursing work is generally encouraged by nurses and doctors alike, qualitative studies have suggested that nurses feel they are having 'dumped' on them the less attractive, unwanted and onerous job responsibilities of others (Adams & Bond 1995) and that their professional identity is being eroded (Doyal et al. 1997, Dowling 1997). Similarly, others have alleged that nurses taking on medical tasks and: 'function[ing] at a lower level in the field of medicine represents an unbelievable human and
intellectual waste' (Castledine 1994:104). Although nurses themselves commonly prefer to think that the ANP role enhances the role of the nurse rather than replacing junior doctors, the recent development of night nurse practitioner (NNP) roles to resite intravenous catheters, record and interpret 12-lead electrocardiograms, insert male urinary catheters, carry out cardiac defibrillation and verify expected patient deaths, has acknowledged that their creation has been a direct result of a commitment to reduce junior doctors hours and save money (Chan 1996, Deacy & Smith 1997).

Whichever viewpoint one takes, there is little doubt that the reduction in junior doctors hours brought about through the ‘New Deal’ policy (NHSME 1991), and the greater emphasis on extended professional training for doctors which arises from the Calman Report (DoH 1993a), places a greater burden on the nurse to undertake some of the work traditionally assumed by junior doctors. Such initiatives must invariably add to the increasingly grey areas between medicine and nursing causing confusion in the doctor-nurse relationship. This confusion has led one author to refer to ANPs as the ‘inbetweenies’ (Dowling 1997).

In summary, this section of the chapter has highlighted that previously entrenched and stereotyped relationships between doctors and nurses, although still in existence in some situations, have begun to erode over the last three decades. Transformations in the relationships between doctors and nurses are complex and have arisen through ‘The New Nursing’ in which nurses seek ‘professionalization’, through doctors seeking to work less hours and change their career structure with improved education and through rapidly changing health care policies. However, what is evident is that whilst changes in policy encourage the disintegration of traditional doctor-nurse roles for ‘cost effective’ purposes and nurses, dissatisfied with their status compared with doctors, strive for a more equal doctor-nurse relationship, doctors themselves, more content with their positions of power, do not always appear threatened or convinced that their relationship with nurses is changing dramatically.
Intraprofessional Relationships

With the exception of the small numbers of men in nursing and the positions of power attained by nurses in managerial positions, there has been little of interest to the sociologist in the study of relationships between nurses; the high proportion of women in nursing exclude examinations of patriarchy, whilst the ‘caring’, ‘feminine’ nature of their work (e.g. Dingwall & MacIntosh 1978, Jecker & Self 1991, Walby et al. 1994, Kendrick 1995, Sweet & Norman 1996) may be assumed to preclude intraprofessional conflict. Hence this may explain the absence of sociological literature on intraprofessional relationships within the nursing profession. Furthermore this oversight extends to the nursing literature where empirical work is scant.

It has been argued that good working relationships amongst nurses contribute towards harmonious interprofessional relationships (Hansen 1995). Yet nurses have also been viewed as a heterogeneous group with widely varying socialization, socio-economic, educational and personal backgrounds (Kavanagh 1989, Wheatley 1996). Since it was suggested earlier in this chapter that there is an increasing demand to better understand interprofessional relationships, this paucity in the literature is surprising. Fortuitously, existing intraprofessional literature has generally been limited to explorations of relationships between CNSs and other nurses, more usually community-based nurses. However, other recent work has included an examination of intraprofessional relationships within teams of district nurses (Griffiths & Luker 1994a), explored models of collegiality among staff nurses working in acute hospital settings (Hansen 1995) and identified a paucity of meaningful relationships amongst nurses working in a psychiatric setting (Kavanagh 1989).

It is uncertain why CNSs, above all others, have aroused the attention of researchers examining intraprofessional relationships in nursing. Various theories include their relative newness to nursing (Griffiths & Luker 1994b), their ability to ‘boundary hop’ between the hospital and the community (Haste & MacDonald 1992, Bignold et al. 1994a, 1994b, 1995a, Hunt 1996), the ‘value for money’ concerns which arise from a lack of role clarity (Haste & MacDonald 1992) and the ongoing debate between the generic and specialist nurse (Griffiths & Luker 1994b). This section of the chapter
examines recent literature in order to contribute towards the understanding of the relationships which exist between POONSs and their nursing colleagues which will be developed later in the thesis.

**Specialist Nurses and Community Nurses**

It has been acknowledged that in specialist areas where uncommon or 'newly emerged' diseases are encountered and where DNs readily admit a shortfall in their knowledge, CNSs are accepted and considered an effective means of delivering nursing care (Haste & MacDonald 1992, Layzell & McCarthy 1993, Griffiths & Luker 1994b). Layzell & McCarthy (1993) for example found that during the emerging days of HIV/AIDS, DNs lacked the knowledge and experience to cope with the demands of this group of patients, so generic nurses benefitted from specialist input. Other conditions where CNSs may be viewed by DNs to make valuable contributions, include children with Cystic Fibrosis and patients with renal disease (Griffiths & Luker 1994b). Similarly, the benefits of specialist nurses in paediatric oncology to DNs and HVs has previously been reported elsewhere (Hunt 1996).

Specialist areas which are not so new or rare and in which DNs feel capable and competent to practice however, bring differing working relationships between CNSs and DNs. Whilst Haste & MacDonald (1992) reported that DNs are largely positive about specialist nurses and that few discrepancies existed between the way that the specialist role was perceived by DNs and CNSs, areas of conflict were highlighted which have been reflected in other studies. One of the problems which has been identified in the relationships between CNSs and DNs, which has lead to conflict between the two groups of nurses, concerns discrepancies in the perceptions of the CNS role (Haste & MacDonald 1992, Williams 1993). Examples of discrepancies between DNs and CNSs have concerned levels of communication and prior consultation between the two groups of nurses: CNSs have perceived themselves to communicate well with DNs whilst DNs have not shared this view. Such variances of opinion have been viewed as an area to focus on to improve the relationships between CNSs and DNs (Haste & MacDonald 1992, Williams 1993).
Particular differences and role ambiguities between CNSs and DNs have developed in palliative care (Griffiths & Luker 1994b) and in the provision of hands-on nursing care (Haste & MacDonald 1992, Williams 1993, Griffiths & Luker 1994b). Palliative care has been reported as an area in which nurses gain tremendous job satisfaction (e.g. Charles-Edwards 1983, Dunlop & Hockley 1990, Haste & MacDonald 1992, Griffiths & Luker 1994b). Because of this, a battle for ‘ownership’ of terminally ill patients may ensue (Griffiths & Luker 1994b) resulting in some DNs acting as ‘gatekeepers’ to specialist nurses, preventing the referral of patients (Griffiths & Luker 1994b). Such battles may be further exacerbated as differing groups of community nurses (e.g. DNs and practice nurses) themselves struggle to grapple with new ways of working and divisions of labour (Damant 1994), further contesting the care of ‘favoured’ patients such as the terminally ill.

Conflicts between CNSs and DNs not only arise when DNs feel deprived of job satisfaction during a patient’s terminal care, but also when DNs perceive themselves to be equally, or in some instances, better qualified than CNSs (e.g. Williams 1993). One solution to this problem has been to suggest that CNSs, whose work extends into the community, possess a community nursing qualification (e.g. Kitson et al.1987, Wade & Moyer 1989, Williams 1993).

The provision of hands-on nursing care has also been reported as a contentious area between CNSs and DNs. District nurses either consider that specialist nurses (frequently Macmillan nurses) provide too little or too much nursing care. It has been acknowledged by both DNs and CNSs that CNSs give a low priority to the provision of hands-on care (Haste & MacDonald 1992). However, whilst some DNs feel that CNSs should provide more hands-on care and that their not providing such care creates more work for DNs (Haste & MacDonald 1992), others feel that they would prefer to provide all nursing care themselves, seeing specialist nurses as either knowledgable resources or interfering (Williams 1993, Griffiths & Luker 1994b).
One of the problems surrounding the provision of hands-on care by CNSs concerns the potential to deskill other nurses. If CNSs are perceived by other nurses as alternatives rather than complementary to themselves, intraprofessional tensions may arise along with the potential to deskill them (RCN 1988, Wade & Moyer 1989, Nash 1990, Williams 1993). Whilst this has been acknowledged as a potential problem, whether deskillling of nurses by CNSs actually occurs remains unknown. One solution to this potential problem however has been to suggest that CNSs adopt a team approach to care (Williams 1993).

From the literature reviewed here, it might be hypothesised that CNSs working in the area of childhood cancer (i.e. a rare disease) may be well received by community nurses. However the importance of who provides hands-on care in the relationships between DNs and CNSs and the significance of community nurse training cannot be overlooked. This research seeks to examine the significance of the provision of hands-on care in the relationships between community nurses and CNSs who work in specialist areas, with rare disorders, who might generally be assumed to have a favourable reception amongst community nurses. It also seeks to explore the significance of professional qualifications and experience in the formulation of relationships between community nurses and CNSs.

Specialist Nurses and Hospital-Based Nurses

The diverse nature of CNS roles has been described earlier in this thesis. In addition to the diversity of roles, work locale differs; CNSs may be based either in the community or the hospital. Time spent in either location similarly varies according to individual posts. Nevertheless, CNSs do cross boundaries between the community and the hospital and the 'boundary hopping' of POONSs in particular has previously been described (Bignold et al. 1994a, 1994b, 1995a, 1995b, Hunt 1996). Therefore it is important to discuss relationships amongst hospital-based nurses as well as those in the community.

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2 In the context of this study the term 'community nurses' hereafter refers to HVs and DNs.
Whilst the researcher is unaware of any studies examining the relationships between CNSs and hospital nurses, one recent American study has defined a model of collegiality amongst staff nurses working in acute hospital settings (Hansen 1995). Here it is contended that major influences upon intraprofessional relationships concern organisational factors. Key elements for creating a sense of ‘collegiality’ amongst staff nurses included involvement of work organisation, loyalty and other work-related aspects which bring about group cohesion (Hansen 1995).

In her study examining the relationships between doctors and nurses Mackay (1993) discussed relationships being affected by differing territorial space: nurses may perceive that doctors are not working if they are absent from the ward since the ward is the nurses’ working world. In contrast the working domain of the doctor is the hospital: commitments are varied, involving out-patient work, theatres, casualty and other wards. She suggests that nurses ‘belong’ to the ward whilst doctors ‘belong’ to the hospital.

If one draws together both the findings from Hansen (1995) and the studies of interprofessional relationships between ward-based nurses and hospital doctors (Mackay 1993), some hypotheses may be drawn about how CNSs may be perceived. Clearly if CNSs are absent from the day-to-day running of wards and other hospital departments, they may both be viewed with suspicion by other nursing colleagues and considered not to be working, much as the doctors in Mackay’s study were perceived. Similarly, the autonomous nature of CNS practice prohibits input into the day-to-day running of the ward, which may be regarded as important for creating a sense of group cohesion (Hansen 1995). This research will examine the extent to which one group of CNSs, i.e. POONs are viewed, by hospital nurses, to participate in the intraprofessional group.
Empowerment

'Empowerment' has recently become synonymous with both 'partnership' and 'involvement' and the concepts have become intertwined (for example see Darbyshire & Morrison 1995, Gormley 1996, Rudman 1996, Sully 1996, Taylor 1996); each underpin government and nursing ideology and concern user involvement. Nevertheless an attempt will be made to distinguish one from another and to focus on the concept of 'empowerment'.

The notion of 'empowerment' is subjective and lacks clear definition (Gibson 1991, 1995, Breton 1994b). Nevertheless it has become a buzz word since the 1960s and is rooted in the 'social action' ideology of that decade and the self-help perspectives of the 1970s (Gibson 1991, Chalmers & Bramadat 1996). Although the concept of 'empowerment' lacks clarity, it is frequently argued that it concerns 'teaching' or 'training' (for example Breton 1994a, Gibson 1995), enables decision-making which allows for personal choices to be made (e.g. Gibson 1991 & 1995, Paton 1993, Breton 1994b, Gormley 1996, Rudman 1996) and is an antecedent to community mobilisation (e.g. Paton 1993, Wallack 1994, Chalmers & Bramadat 1996). It is generally agreed that it implies giving or sharing power with individuals or groups who might otherwise lack power (Gibson 1991 & 1995, Breton 1994a & 1994b, Deveaux 1994, Wallack 1994, Darbyshire & Morrison 1995), it is 'people centred' and it enables a greater sense of taking charge for one's self (e.g. Gibson 1991 & 1995, Deveaux 1994, Darbyshire & Morrison 1995, Chalmers & Bramadat 1996, Gormley 1996). Furthermore Breton (1994b) makes the point that empowerment is an issue which concerns those who lack power - not those who have power but choose not to exercise it. Consequently, as a concept, it is generally appealing and to be encouraged (Gibson 1991 & 1995, Darbyshire & Morrison 1995, Chalmers & Bramadat 1996); as Darbyshire & Morrison (1995) put it: 'Like mom's apple pie, it is impossible not to be 'for' such concepts' (Darbyshire & Morrison 1995:26). Embracing all of these components 'empowerment' has been described as: 'a process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives' (Gibson 1991:359 and 1995:26).
As suggested earlier, the concept of ‘empowerment’ underpins both government and nursing ideologies. Paton (1993) for example, has suggested that reforms which were outlined in the White Paper Working for Patients (DoH 1989a), were seen by the government of the day as a means of empowering citizens. Other recent central government moves to empower patients have developed through additional documents such as the Patient’s Charter (DoH 1996c) in which patients’ rights to health care are mapped out, enabling patients to be more in control of their own health care needs. In addition, the positive approaches to the notion of empowerment described above, although frequently rhetorical (Darbyshire 1994, Darbyshire & Morrison 1995, Gibson 1995, Chalmers & Bramadat 1996, Gormley 1996, Sully 1996), have meant that holistic approaches to nursing currently encourage nurses to empower patients and social workers to empower their clients.

With these points in mind then it is not surprising that the notion of empowerment has been examined in relation to users of services, particularly in health and social services. Although empirical studies in health and social care are extremely limited, the ‘empowering’ nature of social work has been discussed (Breton 1994a, 1994b), whilst different fields of nursing have also employed the concept. It has been argued that community nursing is particularly suited to empowering patients to care for themselves (e.g. Chalmers & Bramadat 1996, Gormley 1996), whilst geriatric nursing has also used the concept to discuss the rehabilitation of immobile, elderly patients (Nazarko 1996). Of particular note, nurses working with children and their families have become especially familiar with the concept through the work of Darbyshire (1994) who explored the experiences of both parents and nurses caring for children in hospital, and Gibson (1995) who examined the process of empowerment of mothers of chronically sick children.

So focused has the age of consumerism become on empowering users of services, such as parents of hospitalised or chronically sick children and others, that the empowerment of health care professionals to be providers of care (with the exception of students (Rudman 1996)), has predominantly been overlooked. Health care professionals have more usually been seen as possessing power over patients/clients
It is probable therefore, in relation to empowerment, that the powers held by health care professionals over patients, have been responsible for this emphasis. However, when health care professionals encounter rare medical conditions with which they are unfamiliar, it is impossible for them to participate in care without being given the required knowledge. This study therefore seeks to address the notion of empowering professionals. More particularly it sets out to examine how empowerment directly affects relationships between professionals, how it is achieved and the effects that different working practices of POONSs have on the ability of other health care professionals to be empowered.

**Partnership**

Like ‘empowerment’, ‘partnership’ has become an ‘in’ phrase of the 1990s. In an age of consumerism and choice, partnerships are evident between industry and other sections of the private, public and voluntary sectors (e.g. Lewis 1993, Dorrell 1995, Pollock 1995, Blunkett 1997). Partnerships are a particular focus between providers and users of health and social services, are widely encouraged and are equated with good practice at government level (e.g. DoH 1993b, DoH 1994, Dorrell 1995, Dorrell 1996, NHSME 1996, DoH 1996b).

Few of those who have written about ‘partnerships’ have attempted to define the concept. However, it is generally agreed that it concerns elements of joint decision-making and goal setting (for example see Wilson-Barnett 1989, Casey 1995, Boosfeld 1995, Taylor 1996). Wilson-Barnett (1989) has suggested that there are many reasons why the idea of partnerships in care have developed. Amongst other contributory factors, she suggests that knowledge about the adverse effects of stress, in which a lack of personal control plays an important role, contributes towards creating partnerships between professionals and their clients. Equally she proposes that partnerships have been seen to provide beneficial therapeutic effects for patients. Thirdly, she contends that consumerism and client choice are desirable phenomena in which partnerships play a part. Hence, like ‘empowerment’, it may be suggested that partnerships in health care are generally a good thing.
The concept of partnerships in health care have been particularly familiar to child health nurses since the development of a ‘partnership’ model in which the family and their expertise is recognised as being of central importance to nursing a child (Casey 1988). Since the development of the Casey Model, there has been further debate about partnerships between child health nurses and parents (e.g. see Casey 1993a, 1993b, Darbyshire 1994, Boosfeld 1995, Casey 1995, Gould 1996, Taylor 1996). The more recent of these have questioned the feasibility of achieving a partnership between the nurse and family due to inequalities of power during decision-making (e.g. Boosfeld 1995, Casey 1995, Taylor 1996). In addition, it has also been suggested that whilst most nurses espouse the philosophy of partnerships in care, ‘partnership’ is frequently payed lip service and not practised (Casey 1993a, 1993b & 1995, Taylor 1996).

‘Partnerships’ between health care professionals have underpinned recent government policy (for example see Dorrell 1996). In spite of this, there are currently only limited signs that nurses are beginning to employ the concept of ‘partnership’ in relation to their working relationships with other health care professionals (Gould 1996). Like ‘empowerment’ the concept has generally been limited to professionals’ relationships with their client groups. As with the notion of empowerment this research seeks to examine the concept of ‘partnership’ between professionals, rather than focusing on those with patients.

**Conclusion**

This chapter has set the scene to examine the professional relationships between POONSSs and their colleagues from three perspectives. Firstly, it has drawn upon literature pertaining to sociology of the professions and to the development of ‘expert’ practitioners in nursing. In so doing it has explored the significance of professional training and experience in defining ‘expert’ to suggest that there are theoretical limitations to the importance that a body of knowledge plays in achieving and defining professional status within health care. Secondly interprofessional and intraprofessional relationships have been discussed to suggest that (a) there is limited understanding of the relationships between nurses and (b) although relationships between nurses and
doctors have become less subservient over the last three decades, their relationships vary depending on levels of seniority, work locations and medical specialties. To date the relationships between medical staff (both junior and senior) and CNSs have not been examined: an oversight which this research seeks to redress.

Lastly the chapter has discussed two popular concepts amongst health care professionals which equate with 'good practice': 'partnership' and 'empowerment'. It has suggested that the concepts are ill-defined and that in a market economy they have been used to focus on relationships between professionals and patients/clients. Vis-à-vis professional relationships, the concepts remain largely under investigated. It has suggested that, in the light of these shortfalls, this research seeks to address how these concepts are constructed by POONSs. In turn, it seeks to investigate how mixed funding sources of POONSs affect their construction.
PART TWO - THE RESEARCH
Chapter Five - Research Methodology (1): The POONS Survey

Introduction

The foundations of this research were discussed in Chapter One; my personal background not only as a POONS, but also as the founder member of POCNSIG were highlighted. The various struggles that were observed during my time as a POONS and the personal acquaintances which subsequently developed during that period were described.

The need to reflect again upon my professional background and personal acquaintances at the outset of this first methodology chapter is simple: firstly, to outline the conceptual themes to be addressed in this research so that the ground for the methodology can be set. Secondly, and more importantly, to introduce the notion that gaining access, maintaining and sustaining access and much of the methodology has been influenced by personal acquaintances and friendships with many of the participants who have been interviewed during two stages of fieldwork.

This research examines how mixed funding sources affect the working practices of POONSs, and the structure and organisation of their services. It further seeks to explore how the divergent strategies of the two main charities funding POONS posts: CLIC and CRMF, influence relationships between POONSs and other health care professionals, working either in the acute hospital sector or in the community. The concepts of ‘empowerment’ and ‘partnership’ are used to study how the philosophies of these charities affect the ways in which relationships between POONSs and PHCTs are constructed. ‘Partnership’ alone, will be explored not only to investigate the influences of voluntary sector funding on the relationships developed between POONSs and hospital colleagues, but also to study how relationships vary between junior and senior hospital staff and POONSs.
Given these questions, two research methods have been adopted. Firstly, to examine the effects of voluntary sector funding upon the work, structure and organisation of POONSs, a quantitative approach has been employed, and a survey was conducted. To then explore the impact of charitable funding upon the relationships between POONSs and their colleagues, a qualitative method was implemented and case studies were carried out. How the POONS survey was planned, implemented and analyzed and the affects of personal acquaintances upon the methodology will be the focus of this chapter. The design of the case studies is discussed in Chapter Seven.

Access
Conducting social research within institutions has often been described as arduous, since difficulties arise when attempting to gain access (e.g. Spencer 1982, Hornsby-Smith 1993). Indeed Hornsby-Smith suggests that:

"...elites and powerful people and institutions are frequently able to deny access because they do not wish themselves or their decision-making processes to be studied, it is inconvenient, they are busy and wish to assert their rights to privacy, and so on" (Hornsby-Smith 1993:55)

Spencer (1982) takes this a step further by suggesting that there are five reasons why large-scale bureaucratic or, 'commonweal' organisations, attempt to control or delimit access to social researchers. These include bureaucratic rigidity and personal threat to careers; the potential threat to the power of that institution; the threat to the subjective reality constructs of the institution; the problem of the legitimacy of the researcher and the problem of exchange. Difficulties may also be encountered when secretaries and junior personnel divert, discourage or refuse requests on their employers' time which may be deemed illegitimate or irrelevant (Hoffman 1980). Such attempts to block access to the researcher pose difficulties to those coming to the institution from the 'outside'. Indeed Spencer continues by suggesting that:
An outside researcher presents a problem for the bureaucracy in that the researcher does not ‘fit’ into the system. He does not fit into the formal chain of command, but moves back and forth at all levels of the organisation. He is not subject to the same rules or constraints as organisational participants. As such the researcher is a relatively uncontrollable element in an otherwise highly controlled system (Spencer 1982:24)

So if gaining access to large-scale organisations such as hospitals is difficult for social researchers due to bureaucratic restraints or the threatening presence of the ‘outsider’, perhaps one solution to gaining access lies in being an ‘insider’. Spencer (1982) suggests that the ‘insider’ gives the greatest access to data, although being on the ‘inside’ is not without its difficulties. He proposes that difficulties arise when publishing, since research conducted by the ‘insider’ may be considered biased which cannot be overcome through insight and knowledge of the researched organisation.

The concept of the ‘insider’ as a means of gaining access to large bureaucratic organisations has thus been introduced. As a previous CNS in the research field, I not only came from within, but I personally knew, or at least knew of, all POONSs who participated in the survey. I also knew many of those interviewed (where hospital-based) during the case studies. In addition, involvement in POCNSIG had gained mutual support for the research to be undertaken: common areas of concern relating to funding and practice had been frequent topics of discussion amongst the group - accessing and recruiting POONSs to participate in the study was consequently an easy task.

Personal acquaintances have previously been used to overcome access difficulties within elite organisations (Hoffman 1980). For example, gaining access to hospital boards of directors has been reported to be so difficult, that ‘sampling based on personal ties’ has been implemented. This involved seeking interviews with members of boards who were either known personally to the researcher or to members of her family.

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Although participants of this study were not selected because of prior difficulties in gaining access, during the second stage of fieldwork (discussed in the Chapter Seven) when PHCTs and hospital-based health care professionals were interviewed, personal connections and continued contact with POONSs, assisted in gaining access. Letters of introduction were also written to managers on hospital-headed writing paper, supplying professional qualifications of the researcher and stating that the study was being conducted in collaboration with the RCN and the UKCCSG. An example of these letters is given in Appendix Two. This not only aided the process of ‘getting in’ but also of establishing credibility, thereby overcoming difficulties of obtaining legitimacy and ‘authenticity of the insider’ (Spencer 1982).

Being able to give names of individual POONSs to HVs, DNs and GPs who participated in the study, acknowledging personal acquaintances with POONSs and when pushed, admitting to being an ex. POONS myself, helped allay suspicions which some PHCT members had when initially telephoned. Using friends, acquaintances and contacts enlisted 100% of POONSs to the survey and a willingness by regional and district hospitals and PHCTs to participate in the case studies. Only three GPs who were approached refused to participate, with a fourth unavailable on arrival: all community nurses and hospital staff obliged.

Social scientists may be perceived as intruders, seen as radicals or disapproving of the establishment:

I was an unknown sociologist encumbered by the variety of stereotypes associated with such a label (such as radical, or socialist, or someone likely to disapprove of the traditional elite board system) (Hoffman 1980:47)

As a POONS I had previously been interviewed for a parallel study of POONSs (Bignold et al. 1994a, 1994b, 1995a, 1995b, Cribb et al. 1994). During this time I became aware of the threat, described by Hoffman, which social scientists may play. This study was being conducted by three social scientists from a large London-based academic institution and was being part-funded by CRMF. At this time CRMF had
just funded their first MPN posts implementing an ‘adult’ model; this had resulted in community, rather than hospital-based, nurse managers and caused a great deal of anxiety for the POONSs concerned. Consequently, suspicion was aroused amongst other POONSs lest a hidden agenda existed.

Hence, CRMF funding social scientists (the ‘outsiders’) to conduct this research created concern amongst POONSs. Being one of several interviewed during the course of the fieldwork, I was aware of the threat that these interviews posed to most POONSs (not at that time having made the transition from nurse to social researcher, I include myself as one of the wary!). Such suspicions confirmed the value of taking the ‘insider’ approach when considering methodological options.

In conclusion, gaining or maintaining access to conduct research in large bureaucratic organisations such as the NHS, can often be difficult. It may be particularly hard if the researcher is perceived to be an ‘outsider’. Close personal relationships between the interviewer and interviewee and prior experience in the field enables a researcher to adopt the ‘insider’ role. In this study this approach resulted in high levels of recruitment during both stages of the research.

**Interviewer Effects**

Being an ‘insider’ and having personal ties with interviewees have implications for the validity of data (Spencer 1982). It is therefore of particular importance to consider the effects that interviewers may have upon their participants. Race, age, social class or status, gender, religion and personal style are reported to have an effect upon the relationships between interviewer and interviewee; commonality of any of these enhances the richness of the data (e.g. Dijkstra 1983, Fielding 1993b). However, research examining the effects of interviewers upon interviewees have focused on studies employing several interviewers (e.g. Dijkstra 1983, Groves et al. 1985). This has led to the suggestion that: ‘[findings] reported as statistically significant are, in all likelihood, not significant at all, owing to the fact that these studies have not taken the effects of significant interviewer variance into account’ (Dijkstra 1983:180).
Nonetheless demographic similarities between investigator and participants were apparent during the POONS survey: not only were professional and social backgrounds shared but all were female and most shared other similarities such as age and ethnicity. The similarity of characteristics enhanced the already existing mutual grounds which were shared.

As regards the case studies, in most circumstances acquaintances between the interviewer and the participants had not been previously established. Nonetheless, some similar interests were shared: senior hospital staff shared concerns regarding the work of POONSs whilst a common understanding of medical vocabulary or a concern to provide optimal care to children with malignant disease and their families was shared with others. Social class and status, race, gender or age were also shared between the researcher and some of the interviewees. Whilst the validity of the data may be questioned when ties exist between the interviewer and the interviewee (Spencer 1982), in this study similar outlooks and understanding of the problems under investigation gave a richness to data. Similarly, interviewer effects were minimized by employing a sole interviewer who shared many traits with participants.

The POONS Survey
The work of CNSs is diverse, resulting in role ambiguity and inconsistency in description (e.g. Harrell & McCulloch 1986, Storr 1988, Wade & Moyer 1989, Smith 1990, Williams 1993). However, studies carried out in both the USA and UK agree similar core components on which this study bases its definition. These include: expert clinical practitioner, educator, consultant, researcher, change agent and more recently, staff advocate (Harrell & McCulloch 1986, Smith 1990, Miller 1995).

Previous experience as a POONS suggested that the service structure and working practices of POONSs are no less diverse than those of other CNSs. Hence, when designing the methodology a wide subject area had to be considered. Key themes concerning the structure and provision of services, professional responsibilities, experiences and qualifications, managerial components and provision of support were to be included in the investigation, along with core components of CNS roles.
To address the diversity of issues and the key themes in this study, the research was designed to describe the work, careers and organisation of POONS services. It was also intended to complement the work of Bignold et al. (1994a, 1994b, 1995a, 1995b) which had been qualitative in nature, taking a case study approach at one regional UKCCSG centre. In addition, discussions with both the DoH, who were funding this study, and the steering group associated with the project, resulted in a more quantitative approach to gain an overall description of nationwide POONS services.

However, neither myself nor the steering group were content to gather quantitative data alone. Firstly, we considered that there were some sensitive issues which needed to be probed. Secondly, it was anticipated that fairly detailed information about areas such as terminal care and bereavement provision would be gathered, in addition to details of previous professional and personal experiences. These considerations required a more open approach than a self-completion questionnaire might allow for.

A semi-structured interview, conducted either by telephone or face-to-face, was the selected method of choice. This would allow for a variety of question formulae and types of information to be collected including open and closed questions on attributes, attitudes and behaviour (Newell 1993). It would enable a wide range of topics to be incorporated; it would also allow for the wide geographical spread over which POONSs were scattered. POONSs are located from as far apart as Aberdeen to Truro and Dublin to Cambridge. POONSs spend much of their day communicating both by telephone and in person. It was therefore considered that either method could be implemented without affecting the quality of the data. Personal acquaintance with participants also facilitated the use of either approach. Face-to-face or telephone interviews were therefore selected according to the distances between the researcher and participants; those interviewees working the greatest distances from the researcher participating in telephone interviews.
The Study Population

The study population included all POONSs from the UK and the Irish Republic (N=43). Those attending POCNSIG, and several POONSs working at children's departments within DGHs who I knew of were included, along with several based at regional paediatric oncology treatment centres who I did not previously know; these were contacted through the 'link member\(^1\) network within PONF. All POONSs were contacted at the outset of the survey and reminded or informed about the project depending on their prior knowledge of the research. At this time names of all Clinical Nurse Managers (CNMs) were identified and written to, informing them of the study and informally seeking their permission for the POONS/s to participate.

A semi-structured questionnaire was designed as an interview tool to collate baseline data on which to build at a later stage in the project, when it was anticipated that focused interviews with a sample of POONSs would be conducted. The questionnaire was constructed in seven sections including work structure, caseload, drug administration, responsibilities and management, documentation, personal details and support; it amounted to 62 open and closed questions (Appendix Three). Prior to interviewing pilot work was carried out. A precoded questionnaire was completed by the researcher during the interview (see page 96). In addition, with permission from the participants, the interviews were tape recorded and the qualitative material gained via the open questions was later transcribed. Although permission to tape record the interviews was gained from all participants and all were tape recorded, only those who participated in the face-to-face interviews were conscious of the tape recording process. Those interviewed by 'phone were recorded using a telephone interviewing device and were therefore informed when the tape recorder was switched on at the outset of the interview and then again when turned off at its completion. The

\(^1\) The 'link member' scheme of PONF is a communication network for paediatric oncology nurses nationally. One and sometimes two paediatric oncology nurses from each regional children's cancer treatment centre volunteers to act as a 'link' between their centre of work and PONF, acting as a communicator between the two organisations. A booklet is produced which is made available to all PONF members listing the names of the 'link' members at each regional centre.
Qualitative components of the questionnaire engendered a limited number of categories with a small range of responses. For simplicity therefore, both quantitative and qualitative data were coded and analyzed with the aid of SPSS/PC+ (Dometrius 1992, Fielding 1993a). Two independent (de Vaus 1991, Norušis 1991, Arber 1993) or experimental (Oppenheim 1992) variables were created concerning the work location and funding organisations of POONSs around which crosstabulations of dependent variables (de Vaus 1991, Norušis 1991, Oppenheim 1992, Arber 1993) were conducted. Due to the nature of the population (i.e. total rather than a sample) probability statistics were unnecessary.

Piloting

*Questionnaire design is a very complex task in interpersonal communication... piloting various versions of the question... must occur* (Bulmer 1984:98)

Prior to undertaking my PhD I had gained a wealth of experience and professional training working with children with cancer and their families, especially with those whose children were dying or who had died. A great deal of professional experience advising other health care professionals (e.g. GPs, consultant paediatricians, other PHCT members and local nursing staff) had also been acquired. To enhance the working relationships with families and health care professionals the skill of diplomacy in communication is of paramount importance. Hence I believed myself to be fairly skilled in the art of interpersonal communication prior to conducting the research. In spite of this, I cannot support Bulmer’s (1984) statement strongly enough. Pilot work during the construction of the questionnaire was a significant influence not only in devising the final version but also in the manner in which the POONS survey was conducted. It also assisted in preparing the guided schedule, utilised during the case studies.

One of the benefits of personally knowing the research subjects was a ready supply of volunteers to assist in pilot work during both stages of the research. Consequently POONSs were happy to give up their time twice to be interviewed during both the
pilot phase and the true fieldwork; both hospital and community health care professionals were similarly obliging. Five POONSs were approached to participate. POONSs were selected according to the length of time they had been in post, their work location and my personal relationship with them. Two were recently appointed POONSs, one who I knew very well, the other hardly at all. The remaining three had been in post for a considerable period of time, were funded by a variety of sources, and worked either alone or as part of a team. One was, and remains, a close friend. The variety of work locations presented the opportunity of piloting both face-to-face and telephone interviews. Pilot work with these volunteers offered me the chance to acquaint myself with techniques, such as telephone interviewing, which were previously unfamiliar. It also enabled me to assess interviewing skills, both with those who I knew extremely well and those less well known; in addition, the opportunity to determine the length of the interview was also proffered and the suitability of questions both to those recently appointed and those more experienced was considered.

My background ensured common professional experiences with POONSs. Nevertheless, an important aspect of piloting the survey was to ensure a common understanding of language (Bulmer 1984). This aspect of piloting proved to be of great importance and interest since it offered the first ever opportunity to discuss definitions of commonly used terms such as 'palliative care', 'terminally ill' and 'off treatment'. It had previously been my belief that all nurses experienced in working with children with cancer had a common understanding of such terms. This proved not to be the case and interesting debates followed.

Although questions were not altered on the final version of the questionnaire, clarification of such phrases was required during interviews to ensure common understanding. Examples included question fifteen (see Appendix Three): it was stressed that all children receiving palliative chemotherapy should be included, not just those receiving palliative, symptom-relieving medication. Similarly question nineteen (Appendix Three) demanded clarification: 'receiving treatment' meant those children receiving chemotherapeutic drugs only, not medication for iatrogenic
disorders caused by the cancer-treating drugs. Piloting the interviews enabled the length of the questionnaire to be extended although minimal alteration in its structure was required. The final two pilot interviews were altered little and incorporated into the analysis.

**Interviewing**

Prior to conducting the survey, POONSs were contacted to discuss the interview format and to arrange a mutually convenient time for this to take place. I was keen that POONSs received a copy of the questionnaire beforehand; when arranging the interview they were asked how far in advance they would like to receive it. This was done for two reasons; firstly a section of the questionnaire examining caseloads required some prior data to be collated. Secondly, personal acquaintance with the participants, instincts as a researcher and prior experience of being interviewed during the parallel POONS study, suggested some anxieties existed - knowing beforehand what would be asked assisted in overcoming any such worries. An additional way of overcoming anxieties about the interview was to produce two versions of the questionnaire, one was precoded to complete at the time of interview and a second, uncoded version was sent out to POONSs. Experience had suggested that nurses, like other health care professionals, were sceptical of research methodologies they did not understand - an uncoded version of the questionnaire was considered less intimidating.

Close friendships may allow for fewer interviews to be cancelled or postponed and greater obligation and trust to be gained (Hoffman 1980). Knowing the work schedules of POONSs, I was pleasantly surprised how few prearranged interviews were cancelled and rearranged at the last minute. It is probable that personal acquaintance with respondents enabled me to be seen as ‘friend’ rather than ‘foe’. The use of the semi-structured questionnaire enabled participants to volunteer as much or as little information as they wished, particularly in the open-ended questions. This seemed particularly important with a close interviewer/interviewee relationship since it enabled participants to answer questions minimally or to talk freely. Affiliation to the profession enabled me to gain the full support of POONSs; 100% of the research population were recruited into the study. The interviews are summed up in Table 5.1.
Table 5.1 Distribution of interview methods with POONSs (N=43)

<table>
<thead>
<tr>
<th></th>
<th>Telephone Interviews</th>
<th>Face-to-face Interviews</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regional POONSs</td>
<td>16</td>
<td>15</td>
<td>31 (72%)</td>
</tr>
<tr>
<td>District-based POONSs</td>
<td>11</td>
<td>1</td>
<td>12 (28%)</td>
</tr>
<tr>
<td>Total</td>
<td>27 (63%)</td>
<td>16 (37%)</td>
<td>43 (100%)</td>
</tr>
</tbody>
</table>

Developments within a study often result in subtle changes in thinking and a new and better research design (Oppenheim 1992). The survey had originally been designed to gather baseline data on which in-depth interviews with POONSs could be built. However greater insight into the work of POONSs had been gained than initially anticipated, due to the quantity of data collected. In addition, early analysis suggested that a second phase of fieldwork would more importantly address intra/interprofessional relationships. Not only had POONSs’ relationships with other health care professionals varied greatly according to their different work locations and funding organisations, but it was an issue which concerned POONSs themselves. The method employed to address the issue is discussed in Chapter Seven.

The Telephone/Face-to-face Interview Debate

As little as twenty years ago telephone interviewing would not be discussed in a social science research student's thesis. Indeed it would not be debated in the thesis of any research student. Telephone survey methodology has only been a feasible means of data collection since the majority of households possessed telephones; it did not really become commonplace until the 1980s (Lavrakas 1987).

As a method, telephone surveys have developed through face-to-face interview techniques; they have reached a respected status as a valid means of gathering information (Lavrakas 1987). It is also suggested that as a method: ‘in many instances it is the preferred approach to surveying’ (Lavrakas 1987:10). In spite of this, telephone interviewing still receives little attention in most text books on social
research students' reading lists (for example see de Vaus 1991, Oppenheim 1992, Gilbert 1993). Such books draw the readers' attentions to the advantages and disadvantages of telephone interviewing compared to other methods. Benefits of telephone interviews include their low cost in travel expenditure and in travelling time. The rapid availability of results when computer-assisted telephone interviewing techniques (CATI) are implemented are additional advantages over door-to-door interviews (Oppenheim 1992, Newell 1993).

Disadvantages of telephone interviewing include under-representation of certain groups of the population such as the sick and disabled, the poor, the young, those who chose to be ex-directory etc. (Newell 1993, Oppenheim 1992). Response rates may also be low if the methodology has been incorrectly implemented (e.g. de Vaus 1991). In addition, interviewers trained in telephone surveying necessitate rigorous apprenticeship when compared to those conducting face-to-face interviews (Newell 1993). Greater skill is required to present questions clearly and to listen carefully as reactions cannot be interpreted by observation.

Little research on telephone interviewing has been documented. The effects of interviewer characteristics and expectations on overall co-operation rates have been reported (Singer et al. 1983). This study, unlike others criticised by Dijkstra (1983) discusses the effects of individual interviewers within the same studies. The authors concluded that interviewers over the age of 35 years often obtained better cooperation from respondents, independent of previous interviewing experience. In spite of this, overall interviewer effects are somewhat smaller than those reported from personal interview surveys (Groves & Magilavy 1986). In contrast, an earlier randomised study comparing field performance and quality of responses in telephone and in-person interviews, reported comparable results between the two methods (Rogers 1976). The quality of responses in Rogers's study were measured by the ability to answer complex items, the willingness to provide personal information, response, validity and consistency of information; measures of field performance included response rate, length of interview, number of contacts required, preferable times for interviewing, respondent preferences and interviewer effects.
In summary studies comparing the effects of telephone interviewing with those conducted face-to-face suggest conflicting results; whilst differences are apparent between telephone and face-to-face methods in some studies (e.g. Singer et al. 1983, Groves & Magilavy 1986), others indicate little or no differences between the two methods (Rogers 1976).

Telephone interviews are often relatively short. However, doctors and other professionals used to spending large amounts of time on the 'phone, have participated in telephone interviews extending beyond an hour (Rogers 1976). POONSs are very used to and comfortable with spending large amounts of their working day liaising with other professionals by 'phone and talking face-to-face with families. This was an important consideration when designing the methodology. Interviewing by 'phone, although novel to some interviewees, was received favourably by POONSs. They also acknowledged that the choice of telephone interviews saved time.

Employing the two interviewing techniques produced similar favourable outcomes to those reported by Rogers (1976). The length of interviews varied from between 40 minutes to two and a half hours, with both a face-to-face and a telephone interview being amongst the shortest and the longest interviews. No difference in the average length of interviews was apparent across the two methods. Similar times and places for interviewing were arranged with all POONSs regardless of the method - only one interview was conducted during an evening. Initial concerns that a lengthy 'phone conversation may block a channel of communication for families or other health care professionals attempting to contact POONSs were allayed - most participants had access to several telephones. There was one POONS who was difficult to locate on the telephone in spite of numerous messages and letters. In addition those interviews which had to be rescheduled were telephone rather than personal interviews. Nevertheless, low response rates often reported in telephone interviewing did not arise. It is probable that both interviewer/interviewee acquaintance and familiarity with the two means of communication accounted for these favourable outcomes.
In conclusion, many of the arguments in favour of telephone interviews including saving time and travel expenditure, have been supported through this study. Since interviewees were not randomised to either telephone or face-to-face interviews, but selected according to their work location, savings of cost and time were particularly valuable. Importantly the use of both telephone and in-person interview methods gave favourable outcomes to the quality of the data and field performance. Fieldwork experiences support the suggestion that telephone interviewing suits professionals who are used to such means of communication (Rogers 1976), especially when personal acquaintance enters the scene.

Telephone interviews during the course of this study were beneficial, saving time and producing a rich quality of data. Nevertheless personal experience has suggested that, when compared to in-person interviews, even when interviewees are personal acquaintances, telephone interviews do not match the warmth of personal rapport. In addition I would like to add a personal disadvantage of telephone interviewing when interviews are lengthy and consecutive - IT HURT MY EARS!

**Summary**

This chapter has discussed significant factors concerning the methods implemented during the quantitative data collection: the POONS survey. However issues such as gaining access, personal acquaintances and piloting, pertinent to both the POONS survey and the case studies, have also been discussed here. In particular the chapter has discussed the benefits of personal acquaintance on ‘insider’ access within bureaucratic organisations, and the effects in this study, of achieving a 100% response rate. It has also suggested that ‘insider’ research facilitated access to participants of the case studies. It has described the research design and the methods employed during the POONS survey and debated issues around several methods such as telephone interviewing and piloting.
Chapter Six - POONSs: Three ‘Funder’ Models of Structure, Organisation and Practice

Introduction
This chapter draws on the POONS data set to describe the practice, organisation and structure of POONS services. It will suggest that the strategies and philosophies of the two main charities funding POONSs: CRMF and CLIC create two distinctive ‘Funder’ models: the Macmillan model and the CLIC model. A third ‘Mixed Funders’ model can also be discerned which has similarities with the Macmillan model, due to the regional location of the majority of post holders in this group. However, there are also some similarities between the CLIC model and the ‘Mixed Funders’ model due to the clinical practices of POONSs in these groups. The distinguishing features of these models are described in this chapter and, where appropriate, similarities between the ‘Mixed Funders’ model and the other two ‘Funder’ models will be drawn. The main characteristics of the three ‘Funder’ models are summarised in Table 6.1. Through the chapter, the scene is set for the second stage of the research. The research method employed in the second stage is discussed in the following chapter and later chapters focus on how differences and similarities between the ‘Funder’ models impact upon the relationships developed between POONSs and other health care professionals with whom they work.

The ‘Funder’ Models of POONSs
The philosophies of CLIC and CRMF conflicted, whilst the strategies of other smaller charities funding POONSs were less well defined (Chapter Three). It was therefore expected that greatest contrast in structure, organisation and clinical practices of POONSs would exist between those funded by CRMF and those by CLIC. The differences in these philosophies resulted in the development of three ‘Funder’ models of POONSs: (1) the CLIC model associated with providing ‘hands-on’ nursing care, (2) the Macmillan model linked to a ‘hands-off’ approach and (3) the ‘Mixed Funders’ model. POONSs identified with the ‘Mixed Funders’ model operated in ways which, in part reflected the CLIC model, and in part reflected the Macmillan model. This resulted in a ‘mixed’ type of care where both ‘hands-on’ and ‘hands-off’
Table 6.1 Summary of characteristics of the 'Funder' models

<table>
<thead>
<tr>
<th>Structure: (1) Location</th>
<th>Macmillan (N=5)</th>
<th>CLIC (N=10)</th>
<th>'Mixed Funders' (N=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All regional</td>
<td>Almost all district</td>
<td>Mostly regional</td>
<td></td>
</tr>
<tr>
<td>(2) Distance of Patients</td>
<td>Shortest distances</td>
<td>Greatest range - two tier service</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical Practices: (1) Structure of Caseloads:</th>
<th>Macmillan (N=5)</th>
<th>CLIC (N=10)</th>
<th>'Mixed Funders' (N=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greatest no. of children with other life-threatening conditions</td>
<td>Very small caseloads; more time spent with children with other conditions</td>
<td>Greatest proportion of cancer pts.</td>
<td></td>
</tr>
<tr>
<td>(a) New patients</td>
<td>Largest no. of referrals; few visits</td>
<td>Few new referrals &amp; patient visits</td>
<td>More home visits</td>
</tr>
<tr>
<td>(b) Terminally ill patients</td>
<td>Greatest no. of patients; least visits</td>
<td>Few terminally ill children; more visits</td>
<td>Psycho-social support given to child</td>
</tr>
<tr>
<td>(c) Bereaved families</td>
<td>Greatest no. of visits; finite visiting</td>
<td>Daily visiting</td>
<td>Varied</td>
</tr>
<tr>
<td>(d) Well children</td>
<td>No visits</td>
<td>Greater numbers of visits</td>
<td>Varied</td>
</tr>
<tr>
<td>(2) On call provision</td>
<td></td>
<td>Provided to all families</td>
<td>Called more by parents</td>
</tr>
<tr>
<td>(3) Hands-on nursing tasks</td>
<td>Minimal; give little chemotherapy</td>
<td>Perform in schools &amp; at hospital Administer 'softer' cytotoxics including oral medicines</td>
<td>Administer new drug protocols</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organisation: (1) Previous experience</th>
<th>Macmillan (N=5)</th>
<th>CLIC (N=10)</th>
<th>'Mixed Funders' (N=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community nurses</td>
<td>General paediatrics</td>
<td>Staff nurses - oncology</td>
<td></td>
</tr>
<tr>
<td>(2) Qualifications</td>
<td></td>
<td>Fewer</td>
<td>Oncology</td>
</tr>
<tr>
<td>More community Teaching, Care of the Dying Consistently 'H'</td>
<td></td>
<td>Inconsistency</td>
<td>Mostly 'G' or 'H'</td>
</tr>
<tr>
<td>(3) Grading</td>
<td></td>
<td>Very little</td>
<td>Varied</td>
</tr>
<tr>
<td>(4) Teaching</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
care was provided. POONSs identified with the ‘Mixed Funders’ model most closely represented POONSs who practised what have been termed both ‘direct’ and ‘indirect’ care (Bignold et al. 1994a) in which POONSs act both as the main providers of care and also enable other community based nurses to act as key workers.

**Being a CLIC-Funded POONS:**

**The Structure**

The most distinct structural feature of CLIC nursing services which underpins the relationships developed between POONSs identified with this model and other health care professionals, which are discussed in later chapters, relate to their geographical location. Nine out of ten POONSs funded by CLIC operated from DGHs and have been identified with what has been termed the ‘District’ Locational model of POONSs (Hunt 1994, 1995). This means that no CLIC nurses visited patients who lived further than 55 miles from the hospital at which they were based, indeed almost three quarters (n=7) lived less than 35 miles away (Table 6.2); they also cared for smaller numbers of children than those associated with the other two ‘Funder’ models; consequently there was a predominance (n=6) of CLIC nurses who worked alone. The district-based nature and related smaller numbers of patients, in keeping with the philosophy of CLIC, had implications for the nature of nursing practice for POONSs associated with this ‘Funder’ model.

**The Clinical Practices of CLIC Nurses**

In accordance with CLIC’s philosophy to provide local services to families caring for children with cancer, only three out of ten CLIC nurses cared for children with other medical conditions; of those who did, they cared for children with chronic illnesses which were not necessarily life-threatening and functioned more like other PCN services. However, whilst PCNs only spend a small proportion of their time caring for children with malignant diseases (Dryden 1986, While 1991), CLIC nurses responsible for caring for children besides those with a malignant disease, reported spending no more than half their time with these other children. The majority of their working days were spent with families caring for children with malignant diseases.
Table 6.2 Furthest distance of patients visited by POONSs

<table>
<thead>
<tr>
<th>Distance of Furthest Patient</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
</tr>
<tr>
<td>&lt; 20 miles</td>
<td></td>
<td>1 (10%)</td>
</tr>
<tr>
<td>&gt; 20 - 35 miles</td>
<td>&lt; 20 miles</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>&gt; 35 - 55 miles</td>
<td>&gt; 20 - 35 miles</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>&gt; 55 - 75 miles</td>
<td>&gt; 35 - 55 miles</td>
<td>5 (18%)</td>
</tr>
<tr>
<td>&gt; 75 - 100 miles</td>
<td>&gt; 55 - 75 miles</td>
<td>9 (32%)</td>
</tr>
<tr>
<td>&gt; 100 - 150 miles</td>
<td>&gt; 75 - 100 miles</td>
<td>3 (11%)</td>
</tr>
<tr>
<td>&gt; 150 miles</td>
<td>&gt; 100 - 150 miles</td>
<td>5 (18%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>10 (100%)</td>
</tr>
</tbody>
</table>

That some CLIC nurses spent as much time as they did with children with conditions other than cancer or leukaemia was a feature distinct to the CLIC model.

As DGHs see relatively few new cancer patients compared with UKCCSG centres (see Chapter Two), it is not surprising that another key feature of the clinical practices of CLIC nurses relates to the number of children with whom they come into contact. Almost half (n=4) had not had contact with any newly diagnosed children during the month prior to being interviewed and half (n=5) the CLIC nurses visited no new patients at home during that same month (Table 6.3). Although similarly few visits to newly diagnosed children were conducted by MPNs, visits by MPNs at this time, as will be demonstrated later in this chapter, were hampered by pressures of work and not by the few children referred to them.
Table 6.3 Estimated number of visits to newly diagnosed children and their families during the month prior to interview, comparing ‘Funder’ models

<table>
<thead>
<tr>
<th>No. of Visits</th>
<th>Macmillan</th>
<th>CLIC</th>
<th>'M.F.'*</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>2 (40%)</td>
<td>5 (50%)</td>
<td>5 (18%)</td>
<td>12 (28%)</td>
</tr>
<tr>
<td>1 - 2</td>
<td>1 (20%)</td>
<td>2 (20%)</td>
<td>9 (32%)</td>
<td>12 (28%)</td>
</tr>
<tr>
<td>3 - 4</td>
<td>1 (20%)</td>
<td>3 (30%)</td>
<td>6 (22%)</td>
<td>10 (23%)</td>
</tr>
<tr>
<td>5 - 7</td>
<td>1 (20%)</td>
<td>-</td>
<td>7 (25%)</td>
<td>8 (19%)</td>
</tr>
<tr>
<td>over 7</td>
<td>-</td>
<td>-</td>
<td>1 (3%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>10 (100%)</td>
<td>28 (100%)</td>
<td>43 (100%)</td>
</tr>
</tbody>
</table>

* See List of Abbreviations

Another aspect of CLIC nurses’ work relates to the smaller number of terminally ill children that they cared for, compared to POONSs associated with the other two ‘Funder’ models. Almost all (n=9) CLIC-funded POONSs had fewer than two terminally ill children currently in their care which was far less than POONSs working in either of the other two models (Table 6.4). The services offered to families caring for terminally ill children were consequently of far greater intensity with proportionally greater numbers of home visits being paid to relatively few patients (see Tables 6.4 & 6.5). Also there are features about the visits to terminally ill children which differ from the other two models. An example of this includes symptomatic management; four out of ten CLIC nurses advised families on therapeutic management of symptoms. Instead greater numbers (n=6) suggested that they had a more active role in providing hands-on nursing tasks than other POONSs. This is described in greater detail below.
Table 6.4 Number of terminally ill children in care of POONSs during the previous month comparing ‘Funder’ models

<table>
<thead>
<tr>
<th>No. of Patients</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
</tr>
<tr>
<td>None</td>
<td>-</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>1 - 2</td>
<td>2 (40%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>3 - 4</td>
<td>1 (20%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>5 - 6</td>
<td>1 (20%)</td>
<td>-</td>
</tr>
<tr>
<td>over 7</td>
<td>1 (20%)</td>
<td>-</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>10 (100%)</td>
</tr>
</tbody>
</table>

Table 6.5 Estimated number of visits to terminally ill children and their families during the month prior to interview, comparing ‘Funder’ models

<table>
<thead>
<tr>
<th>No. of Visits</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
</tr>
<tr>
<td>None</td>
<td>-</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>1 - 5</td>
<td>2 (40%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>6 - 10</td>
<td>2 (40%)</td>
<td>-</td>
</tr>
<tr>
<td>11 - 15</td>
<td>1 (20%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>16 - 20</td>
<td>-</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Over 20</td>
<td>-</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>10 (100%)</td>
</tr>
</tbody>
</table>

* See List of Abbreviations

1 Includes 5 POONSs who had no terminally ill children under their care
Fewer new referrals to childrens’ departments at DGHs not only enabled CLIC-funded POONS to devote more time to terminal care but they also provided a more intense home visiting service both to bereaved families and to families caring for children in full remission. It also enabled a small number of CLIC nurses to provide a 24 hour on call service for all families, regardless of a child’s disease status. In addition nursing care could be offered not only to children at home but also whilst they were undergoing treatment in hospital. Providing an all encompassing care package to families, following them from hospital to home, is in keeping with the CLIC philosophy and link CLIC nurses with a ‘hands-on’ type of nursing practice.

Eight out of ten CLIC nurses were able to maintain follow-up support to bereaved families for an indefinite period of time which was a feature of POONSs practising within this model. An additional characteristic of CLIC nurses' bereavement work consists of the frequency with which they were able to sustain contact with bereaved parents; almost a third (n=3) contacted families within a day of a child’s death and provided daily visiting to bereaved families until such times as it was deemed unnecessary by the nurse. This was unique to CLIC nurses since POONSs associated with the other two models were more likely to make initial bereavement contact with families about a week after a child’s death. Although CLIC nurses offered bereavement support for an indefinite period of time, it is difficult to assess, besides this early intensive follow-up, what else was provided since fewer reported attending a child’s funeral than POONSs within the other two models and similar proportions of CLIC nurses as other POONSs acknowledged significant dates for families, such as birthdays and the anniversary of a child’s death and participated in group bereavement support work.

Nine out of ten CLIC nurses reported visiting families whose children had completed treatment to provide continuing support to them. Whilst this was not unique to CLIC-funded POONSs, their smaller caseloads provided them with more time and so more visits were reported by them to these families. A small number (n=2) were also on call 24 hours a day, seven days a week to all families caring for a child with cancer; a service that was unique to CLIC nurses since most others only provided services
to families caring for terminally ill children. Other CLIC nurses (n=3) would be on
call to some families and not others; the families for whom this provision was made
would usually be selected by POONSs individually.

Hands-on nursing tasks are encompassed in what has been described as ‘direct care’
where POONSs act: ‘as the key worker and main contact person to the family while
at home’ (Bignold et al. 1994a:27). One of the greatest distinctions of being a CLIC-
funded POONS is the importance placed upon hands-on care; equal emphasis is given
to providing nursing care to children and their families at home as it is in hospital
(Tables 6.6, 6.7, 6.8 & 6.9). Of special note was the greater number of blood
transfusions that were administered to children whilst in hospital (Table 6.9) and the
amount of POONSs who took blood from children whilst visiting them at home
(Table 6.8). At regional centres, nursing duties such as administering blood products
are usually ascribed to ward-based nursing staff, whilst sampling blood from CVADs
at home is frequently undertaken by parents if confident and competent, or PCNs
when available. Some nursing tasks were also undertaken at other locations. A unique
feature of being a CLIC nurse was that almost half (n=4) performed nursing tasks
(usually blood sampling) in children’s schools.

CLIC nurses did not administer as many drugs to children at home as POONSs
associated with the ‘Mixed Funders’ model and there were also differences in the
types of drugs they were giving. In particular, they administered more cytotoxic drugs
at home than other POONSs, especially ‘milder’ cytotoxic agents which are given in
low doses, such as Cytarabine, and oral agents such as Methotrexate, Mercaptopurine
or Thioguanine. At regional centres these are more commonly administered by
parents. CLIC-funded POONSs also administered cytotoxic agents such as Vincristine
which are not normally deemed suitable for home administration, due to their short
term side effects (Hodson & Hunt 1993).
Table 6.6 Number of hands-on nursing tasks (estimated) performed by POONSs in own hospital during the month prior to interview, comparing 'Funder' models

<table>
<thead>
<tr>
<th>No. of Tasks</th>
<th>FUNDER MODEL</th>
<th></th>
<th></th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
<td>'M.F.'*</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>3 (60%)</td>
<td>-</td>
<td>12 (43%)</td>
<td>15 (36%)</td>
</tr>
<tr>
<td>1 - 5</td>
<td>2 (40%)</td>
<td>1 (11%)</td>
<td>6 (21%)</td>
<td>9 (21%)</td>
</tr>
<tr>
<td>&gt; 5 - 10</td>
<td>-</td>
<td>3 (33%)</td>
<td>2 (7%)</td>
<td>5 (12%)</td>
</tr>
<tr>
<td>&gt; 10 - 20</td>
<td>-</td>
<td>-</td>
<td>3 (11%)</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>&gt; 20 - 30</td>
<td>-</td>
<td>2 (22%)</td>
<td>2 (7%)</td>
<td>4 (9%)</td>
</tr>
<tr>
<td>&gt; 30</td>
<td>-</td>
<td>3 (33%)</td>
<td>3 (11%)</td>
<td>6 (15%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>9¹ (100%)</td>
<td>28 (100%)</td>
<td>42¹ (100%)</td>
</tr>
</tbody>
</table>

¹ Incomplete response to question

Table 6.7 Number of hands-on tasks (estimated) performed by POONSs in patients' homes during the month prior to interview, comparing 'Funder' models

<table>
<thead>
<tr>
<th>No. of Tasks</th>
<th>FUNDER MODEL</th>
<th></th>
<th></th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
<td>'M.F.'*</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>2 (40%)</td>
<td>-</td>
<td>8 (29%)</td>
<td>10 (24%)</td>
</tr>
<tr>
<td>1 - 4</td>
<td>1 (20%)</td>
<td>-</td>
<td>7 (25%)</td>
<td>8 (19%)</td>
</tr>
<tr>
<td>5 - 9</td>
<td>1 (20%)</td>
<td>-</td>
<td>3 (11%)</td>
<td>4 (10%)</td>
</tr>
<tr>
<td>10 - 14</td>
<td>1 (20%)</td>
<td>1 (11%)</td>
<td>6 (21%)</td>
<td>8 (19%)</td>
</tr>
<tr>
<td>15 - 19</td>
<td>-</td>
<td>1 (11%)</td>
<td>-</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>20 - 29</td>
<td>-</td>
<td>1 (11%)</td>
<td>2 (7%)</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>30+</td>
<td>-</td>
<td>6 (66%)</td>
<td>2 (7%)</td>
<td>8 (19%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>9¹ (100%)</td>
<td>28 (100%)</td>
<td>42¹ (100%)</td>
</tr>
</tbody>
</table>

¹ Incomplete response to question

* See List of Abbreviations
Table 6.8 Types of hands-on tasks performed (estimated no.) in patients' homes during the month prior to interview, comparing 'Funder' models

<table>
<thead>
<tr>
<th>Hands-On Tasks Performed</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
</tr>
<tr>
<td>(a) Hands-On Tasks:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performed</td>
<td>3 (60%)</td>
<td>9¹ (100%)</td>
</tr>
<tr>
<td>Not Performed</td>
<td>2 (40%)</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>5 (100%)</td>
<td>9¹ (100%)</td>
</tr>
<tr>
<td>(b) Tasks Performed:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long-line Care¹</td>
<td>3 (60%)</td>
<td>4 (44%)</td>
</tr>
<tr>
<td>Basic Nursing Skills</td>
<td>2 (40%)</td>
<td>2 (22%)</td>
</tr>
<tr>
<td>Administering blood products</td>
<td>-</td>
<td>1 (11%)</td>
</tr>
<tr>
<td>ROS*/dressings</td>
<td>-</td>
<td>2 (22%)</td>
</tr>
<tr>
<td>Taking blood</td>
<td>1 (20%)</td>
<td>7 (77%)</td>
</tr>
<tr>
<td>Giving drugs³</td>
<td>-</td>
<td>4 (44%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (20%)</td>
<td>2 (22%)</td>
</tr>
</tbody>
</table>

* See List of Abbreviations

¹ Incomplete response to question

² Care of CVADs

³ All drugs, all routes

n.b. totals exceed 100% since more than one task performed by individuals
Table 6.9 Types of hands-on tasks performed (estimated no.) in own hospital during the month prior to interview, comparing 'Funder' models

<table>
<thead>
<tr>
<th>Hands-On Tasks Performed</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
</tr>
<tr>
<td>(a) Hands-On Tasks:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performed</td>
<td>2 (40%)</td>
<td>9 (100%)</td>
</tr>
<tr>
<td>Not Performed</td>
<td>3 (60%)</td>
<td>-</td>
</tr>
<tr>
<td>Total:</td>
<td>5 (100%)</td>
<td>9 (100%)</td>
</tr>
<tr>
<td>(b) Tasks Performed:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long-line Care(^2)</td>
<td>-</td>
<td>2 (22%)</td>
</tr>
<tr>
<td>Basic Nursing Skills</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Administering blood</td>
<td></td>
<td>6 (66%)</td>
</tr>
<tr>
<td>products</td>
<td></td>
<td>1 (20%)</td>
</tr>
<tr>
<td>ROS*/dressings</td>
<td>1 (20%)</td>
<td>1 (11%)</td>
</tr>
<tr>
<td>Taking blood</td>
<td>-</td>
<td>6 (66%)</td>
</tr>
<tr>
<td>Giving drugs(^3)</td>
<td>-</td>
<td>6 (66%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (20%)</td>
<td>4 (44%)</td>
</tr>
</tbody>
</table>

* See List of Abbreviations

1 Incomplete response to question

2 Care of CVADs

3 All drugs, all routes

n.b. Totals exceed 100% since more than one task was performed by individuals
It might be expected that CLIC-funded POONSs would administer fewer cytotoxic drugs in the community than other POONSs at regional centres, due to their lesser experience which arises through smaller numbers of patients. However 'softer' drugs such as Cytarabine are commonly administered by PCNs who work under close supervision from regionally-based POONSs. Other more toxic drugs such as Vincristine are also sometimes administered by PCNs, unaware of the side effects of the drugs they are administering. The administration of drugs such as Cytarabine and Vincristine are a feature of CLIC nurses distinct from the other two groups of POONSs and more closely links CLIC-funded POONSs with PCNs.

The Organisation of CLIC-Funded POONS Services

Recent downgrading of senior nursing posts has aroused much concern since the implementation of the clinical grading structure in 1988 (for example see Gavin 1995). This concern has been exacerbated locally and nationally by CNSs who have historically had the greatest inconsistency in grading, crossing the top three clinical grades: G, H and I (Armfield 1996, Castledine et al. 1996, McGee et al. 1996). CLIC's approach to grading has been to discuss each new appointment with employing authorities individually. This has resulted in the widest range of grades amongst POONSs, with grades ranging from E to I. Although some recent upgrading had occurred at the lower end of the grading hierarchy, it had also occurred at the upper end too, maintaining the greatest discrepancies.

An additional organisational feature concerns the previous experiences and qualifications of CLIC nurses. The negotiation between CLIC and the local employing authorities which occurs when new nursing services are established has historically resulted in posts arising to satisfy the needs of generalist paediatric staff. One result of this has been to employ paediatric nurses into POONS posts from a more generalist background than POONSs associated with the other two 'Funder' models. Whilst more CLIC-funded POONSs had originated from sisters posts than those associated with the other two models, half (n=5) had not previously worked either in the community or in paediatric oncology and fewer (n=2) had undertaken post basic qualifications in cancer nursing than those affiliated to the other two 'Funder' models.
Indeed not all CLIC nurses (n=8) were both Registered General Nurses (RGN) and RSCNs and one had attained neither, practising as an Enrolled Nurse (EN). Teaching certificates (obtained by the majority of POONSs identified with both other ‘Funder’ groups) were limited to one CLIC nurse and reflected the minimal teaching undertaken by all CLIC nurses. The lack of both basic and post basic qualifications amongst this group of POONSs reflects the greater emphasis which they placed upon personal experiences. Whilst POONSs associated with the other two models highlighted professional experiences such as previous jobs in paediatric oncology or community nursing as relevant backgrounds to undertake the work of POONSs, those associated with the CLIC model drew more heavily on personal experiences such as being a mother or serious illnesses (Hunt 1994). The professional qualifications and previous experiences of all POONSs are discussed in greater detail in Chapter Ten.

In conclusion, the main organisational features of being a CLIC-funded POONS were that they obtained fewer basic and post basic qualifications than POONSs identified with the other two ‘Funder’ models, they drew more on personal experiences as a resource, but had previously achieved a higher level of seniority than other POONSs; they did little in the way of teaching and they had the greatest discrepancies in their grading. These characteristics along with the main features of structure and clinical practice are summarised in Table 6.1.

**Being a CRMF-Funded POONS:**

**The Structure**

In keeping with CRMF’s strategy to establish MPN posts at: ‘an appropriate base... usually... within the specialist unit in the Regional Centre’ (CRMF 1992:3), all MPNs were associated with the ‘Regional’ Locational model of POONSs (Hunt 1994, 1995). In common with Macmillan nurses working with adult cancer patients, all MPNs worked as part of a team with other POONSs. Both of these characteristics contrasted greatly with the CLIC model. An additional structural feature of the Macmillan model was that there was a more defined catchment area from which they drew their patients compared to POONSs associated with the ‘Mixed Funders’ model (Table 6.2). The majority (3 out of 5) of MPNs offered an equivalent service to
families living both near to and far from the hospital to which they were attached; this was a feature which differed from the structure of services offered by POONSs associated with the 'Mixed Funders' model and reflected the differences in their working practices. The defined catchment area along with the operational policies of CRMF meant that there were features about the clinical practices of this group of POONSs which differed from the other two models.

The Clinical Practices of Macmillan POONSs

In contrast to the emphasis CLIC nurses put on their ability to provide hands-on nursing care, the main feature of the clinical practices of MPNs lay in their 'hands-off' approach. Working with others to provide such care is the emphasis of the CRMF philosophy and the extent to which this is achieved will be the focus of Chapter Eleven.

A feature of the work of the earliest appointed MPNs who participated in this study, was that emphasis was placed on providing care to terminally ill children and their families and to the bereaved, not only to those with a malignant disease but also to those with other life-threatening diseases (CRMF 1992). Hence the majority (n=4) of MPNs provided advice to families with children with other life-threatening conditions. Unlike CLIC nurses who sometimes spent up to half their working week providing nursing care to children with illnesses other than cancer, MPNs dedicated only a very small proportion of their time to these other children.

Macmillan paediatric nurses currently had the greatest number of terminally ill children to whom they provided the least amount of home visits (Tables 6.4 & 6.5). A feature combining the emphasis placed upon terminal care support with a lack of hands-on nursing care was highlighted through these home visits. In contrast to CLIC nurses, all MPNs provided information to parents about symptomatic management of their child's terminal illness and none performed hands-on tasks during home visits.
Reflecting the emphasis on terminal care and bereavement work, no MPNs did home visits to children who had completed chemotherapy treatment and were well at home, neither did the majority (n=4) administer any form of chemotherapeutic agents; however they all conducted home visits to bereaved families. Indeed the greatest number of visits to such families were carried out by MPNs for a finite period of time. However it was not the same period of time for each MPN since three suggested they visited for a one year period, whilst the other two said that they maintained contact for two years. The process of grief is not uniform (Murray-Parkes 1983, Black 1994). It is therefore not surprising that other organisations which offer bereavement support to families following the death of a child, are not prescriptive in the length of time which they continue to provide this support (Hindmarch 1994). The experiences of childrens’ hospices however indicate that bereavement follow-up is warranted for two to three years (Hill 1994). These experiences have been backed up through the work of Black (1994) who suggests that there is considerable recovery from the depressive phase of a parent’s mourning by the first, or at most second, anniversary following a child’s death. That a feature of the Macmillan model was to provide follow-up bereavement support for one or two years is consistent with the current body of knowledge about the needs of bereaved parents.

In keeping with the emphasis placed upon terminal care and bereavement work, MPNs saw few newly diagnosed children (Table 6.3) inspite of the larger numbers of new referrals made to MPNs during the month prior to participating in the study. It was apparent that terminally ill children came first and that newly diagnosed children were seen when time permitted. Pressures of work meant that such families were often discharged home and children were readmitted for a second course of treatment before MPNs had the opportunity to make their first contact with them. Although this was not unique to MPNs, it was more apparent with this group.
The Organisation of CRMF-Funded POONS Services

CRMF make recommendations about the organisation of MPN services which largely reflect the roles frequently associated with CNSs. In addition to placing emphasis on the collaborative role of working with other health care professionals which will be covered in more detail in Chapters Eleven and Twelve, the roles of educator and researcher are given much emphasis (CRMF 1992). Recommendations are made by CRMF about the professional expertise required and their grades (CRMF 1992). They state: 'Ideally a Macmillan paediatric nurse should be a registered nurse with paediatric oncology qualification or experience, a community qualification or experience and palliative care experience' (CRMF 1992:5). Although recent reviewing of MPN posts by CRMF has led to a more flexible arrangement regarding grading, in keeping with the RCN guidelines on CNSs of 1992 (CRMF 1995), early MPN posts which were established prior to the outset of the study were given guidance concerning clinical grading. They recommended: 'that such nurses be graded at 'H' and that the job description includes the necessary elements in compliance with the guidelines issued on grading' (CRMF 1992:5). In keeping with this statement most (n=4) MPNs were graded at 'H' and the consistency with which this grading was demonstrated is a key feature of being a CRMF-funded POONS.

In response to the criteria set down in relation to professional expertise, a far greater proportion of POONSs associated with the Macmillan model, compared to those within the other two groups, were trained in community nursing and consequently had previous backgrounds working as community nurses, more usually as HVs. Three out of five also held teaching and English National Board (ENB) ‘care of the dying’ certificates. With the exception of cancer nursing training, which had been undertaken in greater abundance by ‘Mixed Funders’ POONSs, these qualifications were a key contributory factor to MPNs being more highly trained than nurses associated with the other two ‘Funder’ models. Qualifications and training will be discussed in further detail in Chapter Ten. Although more CLIC nurses drew on personal experiences than other POONSs, MPNs drew more heavily on the experience of a personal bereavement as being of benefit to their work. It is not possible to know whether MPNs had experienced personal bereavement to a greater extent than other POONSs,
it is probable however that the emphasis placed upon terminal care and bereavement support was responsible for this feature.

POONSs identified with the Macmillan model held the greatest teaching and research commitments of all POONSs. All MPNs taught for at least half a day a week, most (n=3) reporting that between half a day and two whole days a week were committed to teaching and lecturing both informally and formally, locally and nationally, to a variety of health care professionals. These duties also involved curriculum planning and whilst not confined to this group of POONSs, they spent proportionally more time planning curricula than other POONSs. Similarly MPNs were more committed to undertaking research than POONSs associated with the other two models. No CLIC nurses were involved either in research or curriculum planning and few POONSs identified with the ‘Mixed Funders’ model did as much research and teaching as MPNs.

Being a ‘Mixed Funders’ POONS:

The Structure

Most POONSs (65%) were identified with the ‘Mixed Funders’ model. POONSs in this group had been funded from a variety of sources, including the Rupert Foundation and other, smaller one-off charities established to fund POONS posts. Included in the ‘Mixed Funders’ model are also a small number (n=9) of POONSs who had been continuously funded by the NHS (see Figure 6.1). The organisations associated with funding POONSs in this model, unlike CRMF and CLIC with strategic criteria, are predominantly free of dogma, ensuring that posts are, in the main, professionally determined. Characteristics of POONSs associated with the ‘Mixed Funders’ model are therefore less extreme than those of the CLIC or Macmillan models.

The majority (89%) of POONSs associated with the ‘Mixed Funders’ model were located at regional centres and were identified with the ‘Regional’, Locational model of POONSs (Hunt 1994, 1995). The cross section of work locations meant that a wide range of distances were covered to visit patients at home, ranging from less than
Funding Sources

Figure 6.1

No. of POONSs

Present Funding

Macmillan
CLIC
Other Charity
NHS

Previous Funding Source
- Other
- CLIC
- Macmillan
- Continuous
twenty miles to over 150 miles (Table 6.2). The assorted range of distances provided the greatest diversity of services to families compared to those associated with the other two models: a two tier structure existed in which POONSs frequently visited families living in close proximity to the hospital but infrequently visited those families living the furthest distances. Given the diversity of funding organisations associated with POONSs identified with this model, it is not surprising that the variance in the work location and the wide range of distances they covered to make home visits, resulted in the greatest variety of practices amongst POONSs.

The Clinical Practices of 'Mixed Funders' POONSs

Being less bound by charity strategies, POONSs associated with the 'Mixed Funders' model worked in an individualistic manner within their local environments, satisfying the needs of their particular units, in which they provided a mixture of both 'hands-on' and 'hands-off' nursing care. It also enabled a greater proportion (79%) to provide care solely to children with malignant disease. However the most significant feature is their relationships with newly diagnosed children and their families. Although they were referred slightly smaller numbers of newly diagnosed children than POONSs identified with the Macmillan model, 'Mixed Funders' POONSs provided the greatest numbers of home visits to these children and their families (Table 6.3). This has particular implications for PHCTs and will be discussed in further detail in Chapter Eleven.

POONSs within this group share unusual features in the provision of terminal care to children and their families. In particular they said that they gave psycho-social support to dying children not just to childrens' families. This type of support featured rarely amongst MPNs and never amongst CLIC-funded POONSs. In recent years childrens' rights have become increasingly acknowledged, which have been recognised through the conception of The Children Act (DoH 1989b). More particularly the rights of children with life-threatening diseases to participate in decisions affecting their care and to talk openly about their illness, have been highlighted through the ACT Charter (1994). Though most childrens' nurses purport to acknowledge these rights when nursing sick children, recent studies suggest that
paediatric nurses commonly work in ‘partnership’ with parents, recognising them to be the expert care providers, rather than communicating directly with the sick or needy child (Darbyshire 1994, Casey 1993, 1995). The acknowledgement by POONSs associated with the ‘Mixed Funders’ model, to recognise the need to support dying children and not just families caring for them, epitomises the ethos of children’s nurses. Recognition of these needs was clearly not just unusual amongst POONSs but amongst children’s nurses generally. The reason why this feature is ascribed to POONSs affiliated with this model is unclear. However, the greater proportion of POONSs who had worked in the field of paediatric oncology immediately prior to taking up their posts as POONSs, during which time expertise will have been gained in this area, may account for this characteristic (Table 6.10).

**Table 6.10 Previous location of work, comparing ‘Funder’ models**

<table>
<thead>
<tr>
<th>Place of work prior to becoming a POONS</th>
<th>FUNDER MODEL</th>
<th>TOTAL (N=43)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CLIC (N=10)</td>
<td>Macmillan (N=5)</td>
</tr>
<tr>
<td>Regional Centre</td>
<td>3 (30%)</td>
<td>2 (40%)</td>
</tr>
<tr>
<td>Other paediatric dept.</td>
<td>3 (30%)</td>
<td>-</td>
</tr>
<tr>
<td>Community</td>
<td>2 (20%)</td>
<td>3 (60%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (20%)</td>
<td>-</td>
</tr>
</tbody>
</table>

* See List of Abbreviations

It was widely recognised by all POONSs that PHCTs lacked knowledge to provide skilled care to families caring for children with malignant disease. Although it was often discouraged by managers and seldom formalised, most (93%) POONSs provided an on call, out-of-hours service to bridge this gap in the knowledge of PHCTs. The way in which this service was provided however differed. There were characteristics about the nature of being on call and providing out-of-hours cover to families that were associated with this group of POONSs. They less commonly planned visits to terminally ill children during unsocial hours than other POONSs, unless extremely busy. However to reflect the lack of planned evening or weekend visits, they were more commonly contacted by parents caring for dying children at home, through their
'on call' systems. In contrast, this group of POONSs were contacted the least by families whose children were not terminally ill. It is probable that this is related to the fact that only POONSs in this 'Funder' group did not make themselves available on an 'on call' basis to any families, regardless of a child's state of health. The lack of on-call provision by the few who did not provide it, was not determined through personal choice but through managerial decisions. One POONS team in particular had recently undergone changes in staff and the on-call service had temporarily been withdrawn until the new POONSs had been sufficiently orientated to feel confident and competent to make the decisions demanded of them when being on-call. Whilst this research did not seek to address the benefit of POONSs being contactable 24 hours a day, to families caring for terminally ill children, the implications which this had for PHCTs will be discussed further in Chapter Eleven.

Hands-on nursing care\(^1\) performed in patients' homes was an aspect where there were some similarities between POONSs associated with the CLIC model and those associated with the 'Mixed Funders' model (see Tables 6.7 & 6.8). However, the hands-on care provided by those identified with the 'Mixed Funders' model was frequently restricted to tasks which were perceived to require specialist nursing skills in which PCNs and/or DNs were untrained; a particular example included the types of drugs which they administered. Not only did proportionally more 'Mixed Funders' POONSs administer drugs to children at home (Table 6.8) but they administered or supervised parents in the administration of new drug protocols such as Thiotepa and continuous Adriamycin, given to terminally ill children whose families were reluctant to withdraw active treatment from their children. Such treatments are complex to administer and should be administered by nurses experienced in paediatric oncology (Schaffner 1984, Hodson & Hunt 1993); they require close working relationships between paediatric oncology consultants and POONSs and necessitate careful monitoring, the co-ordination of which is best achieved through childrens' cancer treatment centres (Lange et al. 1988, Close et al. 1995).

\(^1\) Defined as any practical nursing task including helping with washing, administering drugs, removing sutures and caring for CVADS.
The Organisation of 'Mixed Funders' POONS Services

POONSs associated with the 'Mixed Funders' model had greater flexibility to establish their services than those identified with the other two 'Funder' models, since individual charities funding them worked closely with health care professionals to accommodate the needs of particular centres. The subsequent close relationships which developed between the funding bodies and health care professionals had implications for the organisation of POONSs services within the 'Mixed Funders' model.

A particular organisational feature attributed to this group of POONSs relates to their previous professional backgrounds; in particular, the level of seniority from which they entered their present post, and their professional qualifications. Almost a third (32%) had previously worked as staff nurses (SNs), which was more junior than POONSs identified with the CLIC model, who had all previously held sisters posts either in the community or in the acute sector (see Table 10.3). Eight out of ten POONSs associated with the 'Mixed Funders' model who had previously worked as SNs had been promoted internally and in some cases were responsible for establishing the POONS service in which they worked. Since several charities associated with these POONSs were established at the regional centres where they were located, it is possible that they were in a position to work directly with these charities which facilitated their promotion into a POONS role. Clinical nurse specialists have been described as entrepreneurial with dynamic personalities and possessing excellent communication skills (Riehl & McVay 1973, Hamric & Spross 1989, Miller 1995, Arnfield 1996); rather than becoming ward sisters it is probable that such nurses took up the challenge of establishing POONS services at a time when the specialty was beginning to emerge. They had lengthy careers in paediatric oncology and almost half (43%) held certificates in cancer nursing; this was proportionally more than those associated with the other two models. Related to the greater preponderance of POONSs who had been appointed internally, fewer 'Mixed Funders' POONSs had previously worked as community nurses compared to CLIC nurses and MPNs (for further discussion on the professional training and experiences of POONSs - see Chapter Ten).
Conclusion

Drawing on descriptive data from the POONS survey, this chapter has outlined the key features of structure, clinical practice and organisation incorporated into the three 'Funder' models identified with POONSs. These have been summarised in Table 6.1. In so doing, it has illustrated that the opposing strategies of CLIC and CRMF have been responsible for creating great differences in the work of POONSs identified with these two models. In particular, it has noted that the ideals of CLIC to provide a local all encompassing service to children and their families, render the greatest amount of 'hands-on' nursing care and best fits with what Bignold et al. (1994a) describe as 'direct' care. In contrast, the provision of 'expert' regional teams, financially supported by CRMF, yields the highest level of 'hands-off' nursing care which is more akin to the 'indirect' model (Bignold et al. 1994a). Those POONSs less bound by the strategies of charities categorised as the 'Mixed Funders' model practised in ways which employed both 'hands-on' and 'hands-off' nursing to create a 'mixed' type of care.

Along with the degrees of flexibility afforded to POONSs identified with the 'Mixed Funders' model, there are a number of factors which may influence the extent to which 'hands-on' or 'hands-off' nursing care is practised by POONSs incorporated into this 'Funder' model. Firstly, there are a small number (n=3) of POONSs identified with the 'Mixed Funders' model who are attached to DGHs and who may, due to the nature of their small caseloads, function more like CLIC-funded POONSs. Secondly, the limited number of PCN services within the UK (Whiting 1988, 1989, 1993, 1995 Godfrey 1996) may be an influential factor. It is probable that in areas where PCN services operate, 'hands-off' care prevails, with PCNs working in 'partnership' with POONSs to provide any nursing care required (Gould 1996). Thirdly, it is possible that the previous experiences of POONSs affect the degrees to which 'Mixed Funders' POONSs provide 'hands-on' care. Those with lengthy careers in paediatric oncology but who attain lower levels of seniority (see page 122 & Table 10.3) may feel disinclined to 'let go' of 'specialist' nursing skills, choosing to continue practising such skills in patients' homes. This point is discussed further in Chapter Eleven in relation to 'partnerships' between POONSs and PHCTs.
In spite of talking about these three models, there are two main models which are charity-determined - the CLIC model and the Macmillan model. The third model - the 'Mixed Funders' model - to which the majority of POONSs are affiliated, is on the whole, professionally-determined. However, there are some POONSs who could theoretically fit into other models. In particular, there are some features of clinical practice, structure and organisation which could associate some district-based POONSs with a CLIC-type model. These will be discussed in greater detail later in the thesis. Equally there are features of these same district-based POONS services, especially where professionally-directed, which are better suited to sustaining their association with the 'Mixed Funders' model. An example here includes the limited 'hands-on' care provided to children whilst in hospital. Where appropriate throughout this thesis, analogies will be drawn between the POONSs associated with the CLIC model and the district-based 'Mixed Funders' POONSs.

In addition to the key features of structure, clinical practice and organisation, data from the POONS survey, which is drawn upon in Chapters Eleven and Twelve, also indicate that some key differences between the three 'Funder' models existed in the ways POONSs work with other health care professionals. Furthermore, POONSs themselves suggested during the interviews, that both the pleasures and the stresses encountered in the relationships they develop with other health care professionals warranted further investigation. Given the differences in the relationships with other health care professionals between POONSs associated with the three 'Funder' models, the descriptive nature of the survey which hindered theory building (see Chapter Seven), and the aspirations of both POONSs and the steering group, to determine whether one 'Funder' model was any 'better' or 'worse' than another, a second phase of the research evolved to examine the views of health care professionals working with POONSs within the three 'Funder' models. The broad cross section of health care professionals with whom POONSs regularly work, transcending both community and hospital settings (see Chapter Two), the 'sensitive' nature of the examination and the depths it was hoped to probe to (see Chapter Seven), leant towards a case study approach. The methodology adopted during the second stage of the research is discussed in the following chapter.
Chapter Seven - Research Methodology (2): The Case Studies

Introduction
This chapter discusses the qualitative component of the research. Chapters Five and Six suggested that a second phase of research evolved through analysis of the first tranche. From the POONS survey, an hypothesis emerged suggesting that the relationships between POONSs and other health care professionals, influenced by differing levels of 'specialist knowledge', vary according to the work location and the funding organisations affiliated with POONSs. A second qualitative phase of fieldwork therefore emerged to explore the extent to which the divergent strategies of the two main charities funding POONSs: CRMF and CLIC influence these relationships. It was intended to further examine professional relationships by exploring the perceptions and experiences of health care professionals working with POONSs. In addition, it aimed to investigate how health care professionals working with POONSs perceive the 'specialisation' of POONSs and whether these perceptions affect their professional relationships.

The nature of relationships between POONSs and those who they work with, and the effects of various charitable organisations upon these relationships are complex. Furthermore, probing health care professionals about their relationships with colleagues may be deemed 'sensitive' (Stewart & Shamdasani 1990, Lee 1993, Mason 1997). Both these factors leant towards a detailed case study approach. The research design of this second phase is the focus of this chapter; it discusses the merits of conducting qualitative research; it also examines how qualitative research may enhance quantitative methodology through 'triangulation'; it highlights the qualitative, case study methodology adopted during this study and debates individual and group interviewing. Finally this chapter outlines the hospitals which participated in the case studies and their surrounding areas.
Qualitative Research

There is little consensus on whether or not qualitative research should be differentiated from quantitative research and how it should best be defined (Coffey & Atkinson 1996, Mason 1996). Furthermore, although their approaches may differ, it is generally agreed amongst recent authors that there are not only dozens of ways in which qualitative research can be approached and conducted (for example see Silverman 1993, Miles & Huberman 1994, Coffey & Atkinson 1996, Mason 1996) but that there is no single way of managing analysis (e.g. see Bryman & Burgess 1994, Coffey & Atkinson 1996, Mason 1996). One approach to classifying the ways in which qualitative research is undertaken is to examine preferred styles of collecting data i.e. methods (Silverman 1993, Miles & Huberman 1994). In adopting this approach Silverman (1993) identified four major methods: observation, analysing texts and documents, interviews and recording and transcribing. Taking a different stance, Jennifer Mason (1996) in her recent book about conducting qualitative research suggests that methods should be adopted according to the 'intellectual puzzle' the researcher is attempting to address. That is, that researchers should be clear about the essence of their enquiry, formulating a clear set of research questions before selecting the most appropriate research methods. Although different approaches to qualitative research have been taken, the four methods described by Silverman (1993) are generally embedded into other classifications.

Different meritorious claims have been made for conducting qualitative research. Examples include: providing a 'deeper' picture than the variable-based correlations provided by quantitative studies (Fielding 1993b, Silverman 1993), inducing hypotheses and promoting theory building (e.g. Glaser & Strauss 1967, Fielding 1993b, Hammersley & Atkinson 1983, Silverman 1993, Miles & Huberman 1994, Mason 1994, 1996), providing authenticity and a cultural representation of the world (Silverman 1993) or what others have called a 'naturalist' perspective (Miles & Huberman 1994) and providing 'social explanations' to phenomena (Miles & Huberman 1994, Mason 1996). Another key interest in qualitative methodology concerns linking qualitative with quantitative data (e.g. see Zelditch 1982, Fielding & Fielding 1986, Corner 1991, Mason 1994, 1996). This component is highlighted
below in a discussion on triangulation.

Given both the ‘intellectual puzzle’: namely to explore how the philosophies of charities associated with funding POONSs influence the construction of relationships between POONSs and other health care professionals, and the sensitive nature of elucidating information about colleagues from health care professionals working with POONSs (see Stewart & Shamdasani 1990, Lee 1993, Mason 1997), interviewing was deemed the most appropriate method of data collection. This was done in a case study format at three selected areas. How the locations were selected and the interviews conducted are discussed in detail below.

**Triangulation**

> qualitative work can assist quantitative work..... selecting survey items to construct indices, and offering case study illustrations.... survey data can be used to identify individuals for qualitative study and to delineate representative and unrepresentative cases (Fielding & Fielding 1986:27)

Different methodological techniques yield data on different aspects of a phenomenon (Mason 1996). This technique has been referred to as ‘triangulation’ and often implies combining qualitative with quantitative research methodologies. ‘Triangulation’ is a combination of research methods which are employed to study the same phenomenon or set of research questions (Denzin 1970, 1978, Corner 1991, Mason 1994, 1996). In this study a methodological triangulation (Denzin 1970, 1978) technique was developed through adopting a two-stage, quantitative and qualitative approach to examining professional relationships between POONSs and other health care professionals. Methodological triangulation enhances research validity (Macdonald & Tipton 1993), and combines the ‘hardness’ and ‘the depth and reality’ approaches to data collection; it also combines quantitative and qualitative fieldwork methods (Zelditch 1982). In addition data triangulation (Denzin 1970, 1978) was implemented through collecting data from two sources - firstly from POONSs in the form of a survey and secondly through interviews with health care professionals working with
POONSs. Data triangulation allows for validation and confirmation of quantitative research findings and offers an explanation of typical or unexpected events (Corner 1991). In this study triangulation functions in two ways. Firstly the qualitative data augmented i.e. validated the quantitative data. Secondly, the qualitative data painted a different perspective to the survey data and promoted theory building (see Glaser & Strauss 1967, Hammersley & Atkinson 1983, Silverman 1993, Miles & Huberman 1994, Mason 1994, 1996).

Case Study Methodology
To explore the relationships between POONSs and others with whom they work and to enable: 'strategies for discovery' (Fielding 1993b:136) to develop, a case study approach was designed. Case studies are: 'the preferred strategy when ‘how’ and ‘why’ questions are posed …on a contemporary phenomenon within some real-life context' (Yin 1994:xiii). In this research, case studies were adopted to conduct interviews because they allowed for a broad spectrum of health care professionals at each of the three selected sites to be interviewed (see Yin 1993). This was important to gain a wide perspective on the influences of the strategies adopted by the organisations associated with funding POONS services, on professional relationships.

The case studies comprised focused, in depth, tape-recorded interviews with multidisciplinary health care professionals, working both in the community and in hospitals (for an example of an Aide Memoire see Appendix 4). Three hospital locations were selected as examples of each of the ‘Funder’ models associated with POONSs (see Chapter Six). From the POONS survey data, there was little difference between hospitals employing POONSs within each of the three ‘Funder’ models. Locations were therefore selected either for personal convenience to the researcher, reduced cost to the research budget or both. Typical of the organisations and practices of POONSs funded by CLIC, Westlands District Hospital1, selected to represent the CLIC model, is a district hospital which employed a single POONS. It was selected

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1 The names of all the hospitals participating in the case study interviews are fictitious and have been created to reflect the environment in which they are located.
as a case study site because accommodation with a relative was available within the area for the duration of the case study. Those exemplifying both the Macmillan model: the Northern City Children's Hospital, and the 'Mixed Funders' model: the Southern Regional Hospital were regional centres employing teams of POONSs. The Northern City was selected to reduce costs, whilst both PHCTs and hospital-based staff at the Southern could be interviewed within daily commuting distance of the researcher's home, making this location suitable for both reduced cost to the research budget and personal convenience to the researcher. A fourth site was selected for a pilot study: Moorcroft Children's Hospital. This epitomised the majority of POONS services in that it was a regional centre, employing a team of POONSs who operated within the 'Mixed Funders' model. Like the Southern, this location was accessible from the researcher's home on a daily basis.

Both individual and group focused interviews were conducted, depending on availability of participants. Following completion of the pilot work 65 interviews were conducted between October 1994 and April 1995. Data from the pilot site were included in the analysis. All four sites are described in detail below and the interviews are summed up in Table 7.1. The tape-recorded interviews were transcribed and stored in Wordperfect 5.1. Although qualitative software packages are commonly recommended to assist with the analysis of large amounts of data (e.g. Fielding 1993b, Miles & Huberman 1994), unless expert in using the software, it can be a lengthy and tedious process to the novice (Fielding 1993a). Therefore, with the aid of Wordperfect 5.1 only, analysis was conducted through the development of a conceptual framework which was generated using a data reduction, display and verification model (Miles & Huberman 1994). Data was 'reduced' (Miles & Huberman 1994:10-11) with the emergence of four substantive themes: relationships between POONSs and nurses, relationships between POONSs and doctors, knowledge and experience, and teamwork. These themes were colour coded on the transcripts and 'cut and pasted' into separate word processed files, aiding 'display' (Miles & Huberman 1994:11). From these themes, sub categories emerged which further reduced the data. This process facilitated conceptualisation, resulting in 'verification' (see Miles & Huberman 1994:11-12).
The Study Population

It has been suggested elsewhere in this thesis that the nature of working relationships between POONSs and other health care professionals is complex. A broad cross-section of both hospital and community-based health care professionals were consequently interviewed including senior and junior medical and nursing staff, GPs, HVs and DNs. Paediatric community nurses were not included since a uniform picture was required within each participating area. Limited PCN services (Godfrey 1996, Whiting 1988, 1993, 1995, 1997) necessitated their exclusion from this study. Following consent from Clinical Directors, where the staff were not already personally known to me, the names of social workers, consultants and ward sisters were passed to me through POONSs at each of the participating centres. They were then contacted in turn and asked to participate in the interviews. Snowball sampling (Arber 1993) was then implemented to recruit junior medical and nursing staff. Hospital-based interviewees are summed up in Table 7.1.

Twelve PHCTs associated with each of the three hospitals taking part in the study were selected to allow for individual differences in a child’s disease status and care; they were selected by requesting the names from POONSs of six PHCTs who had most recently experienced the death of a child and six with newly diagnosed children registered at their practice. Interviews were held in each with GPs, HVs and DNs (Table 7.1). Primary health care teams were located in a variety of environments - urban, suburban and rural and were at varying distances from the hospitals; those associated with regional centres were no more than fifty miles away whilst those working with the POONS service at Westlands were largely located within the town centre. Primary health care teams had had different degrees of contact with POONSs; due to the rarer nature of childhood malignancy at DGHs and a dearth of new patients at Westlands during the preceding two years, some of the interviewees from the Westlands area had not worked with the CLIC nurse for approximately five years. Those working with POONSs attached to regional centres had all had contact within the last six months.
## Table 7.1: Interviews conducted at case study sites

<table>
<thead>
<tr>
<th>INTERVIEWEES</th>
<th>Southern Regional Hospital</th>
<th>Westlands District Hospital</th>
<th>Northern City Children’s</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hospital-based staff:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Senior Medical Staff (Consultants/Associate Fellows)</td>
<td>2 (I)</td>
<td>2 (I)</td>
<td>3 (I)</td>
</tr>
<tr>
<td>Junior Doctors (SHO/Registrar)</td>
<td>1 (G)</td>
<td>1 (I)</td>
<td>1 (I)</td>
</tr>
<tr>
<td>Ward Sister/OPD Sister</td>
<td>1 (G)</td>
<td>1 (I)</td>
<td>3 (I)</td>
</tr>
<tr>
<td>Junior Staff Nurses</td>
<td>1 (G)</td>
<td>1 (G)</td>
<td>1 (G)</td>
</tr>
<tr>
<td>Malcolm Sargent Social Worker</td>
<td>1 (I)</td>
<td>1 (I)</td>
<td>1 (G)</td>
</tr>
<tr>
<td><strong>Community-based staff:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP (newly diagnosed patients)</td>
<td>5 (I)</td>
<td>4* (I)</td>
<td>4 (I)</td>
</tr>
<tr>
<td>GP (terminal care)</td>
<td>4 (I)</td>
<td>3* (I)</td>
<td>4 (I)</td>
</tr>
<tr>
<td>HV (depending on age of child)</td>
<td>4 (1G,3I)</td>
<td>3 (2I,1G)</td>
<td>1 (I)</td>
</tr>
<tr>
<td>DN (depending on disease status of child)</td>
<td>6 (2G,4I)</td>
<td>3 (I)</td>
<td>6 (I)</td>
</tr>
<tr>
<td><strong>TOTAL NO. OF INTERVIEWS</strong></td>
<td>25 (19I, 6G)</td>
<td>17* (14I, 2G)</td>
<td>24 (22I, 2G)</td>
</tr>
</tbody>
</table>

* 1 GP included twice since interviewed both in connection with a newly diagnosed child and a terminally ill child

I - Individual Interviews
G - Group Interviews (2-4 interviewees)
**Individual and Group Interviewing**

The intention of this research was to seek the opinions of health care professionals working with POONSs under a variety of conditions in order to explore a dimension of attitudes. The nature of the exploration concerned opinions and experiences of health care professionals regarding the work of particular POONS/s who they had worked with. Some interviewees had known me for a long time whilst others knew that I was personally acquainted with ‘their’ POONS. Hence the topic for discussion could be considered somewhat ‘sensitive’ (Stewart & Shamdasani 1990, Lee 1993, Mason 1997). Open-ended, focused or unstructured interviews allow the researcher to explore peoples’ views, to probe deeply, to uncover new clues, to open new dimensions of a problem and to establish both a variety of opinions concerning a particular topic and relevant dimensions of attitudes (e.g. Palmer 1928, Burgess 1982, Reinhartz 1992, Fielding 1993b). Hence such methods were deemed appropriate to address the research question whilst allowing for the sensitivity demanded.

Three forms of unstructured interview have been described: non-directive, group and conversation (Burgess 1982). Disadvantages of group interviews have been well documented (e.g. Burgess 1982, Hedges 1985, Fielding 1993, Kitzinger 1994). Nevertheless, their usefulness in researching sensitive subjects such as interviewing children, and more recently attitudes towards AIDS, are similarly well recorded (see Burgess 1982, Hedges 1985, Stewart & Shamdasani 1990, Croft & Sorrentino 1991, Fielding 1993b, Kitzinger 1994). Additional benefits of group interviewing include cost and time savings and a means of drawing out a common view or a range of views (Fielding 1993b). Group interviews are also a beneficial means of aiding participants to consider subjects in ways that they would not normally be accustomed:

> Often people in interviews are visibly (and with difficulty) addressing questions they have never really asked themselves before. So much of our normal behaviour is organised and motivated at sub-conscious or semi-conscious levels, and so much is habituated and automatic, that even a well organised and self-aware person typically has only very limited insights into his own attitudes and motivations (Hedges 1985:73)

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A review of the psychological literature has suggested that the better acquainted with each other group members are, the less self-disclosure is likely to occur during group interviews, especially if subject matter is non-intimate (Nelson & Frontczak 1988). However, in a study examining the relationship between analyst influence and acquaintanceship in group interviews in the advertising industry, it was concluded that existing knowledge about processes at work in focus groups is limited, prescriptive and unsupported by rigorous research (Nelson & Frontczak 1988).

As little is known about the dynamics of group interviews, the advantages of the group interview methodology were considered during this research. The intention was to interview as many health care professionals as possible at each of the three sites. Therefore, where possible group interviews were deemed to be the most appropriate type of unstructured interview. This was a particularly advantageous method to employ with junior staff who were more numerous than senior nurses and doctors and who had been reported by most POONSS to have limited contact with them. Small group interviews were also considered appropriate where more than one GP, HV or DN within a practice had been involved in caring for a child and their family.

Where group interviews were not to be implemented due to restricted numbers (for example only one Sargent social worker employed within the unit, only one HV responsible for a family’s care or the inability of paediatric consultants or sisters to be available for interview at the same time) individual interviews were considered. Of the two other forms of unstructured interview described by Burgess (1982) the conversation method was implemented. Foote-Whyte (1982) suggests that non-directive interviewing is an inappropriate method to implement during research work, describing his study of human relations in restaurants thus:
I decided that I would be just as non-directive as I could. I began each interview simply by asking the informant to tell me whatever he cared to that was important to him about the job situation. The usual answer was: 'what do you want to know?' Some informants were willing to respond to questions but no one poured out his feelings in response to my general invitation. Rather the approach seemed to make the informants quite uneasy, and I quickly shifted to providing a good deal more structure in the interview

(Foote-Whyte 1982:111)

Following pilot work, the first interview to be conducted was with a consultant paediatric oncologist. Curious about the methodology, he quizzed about the methods and means of analysis (he is an old friend of mine!). He failed to understand research methodology other than large scale randomised controlled trials which he is more used to co-ordinating rather than participating in. In a similar vein, another consultant repeatedly asked me during the interview what it was that I wanted to know, whilst a GP failed to comprehend that tape recorded interviews formed part of the analysis; he anticipated that I would arrive at his surgery with a list of questions which he would be expected to answer. Such expectations, which had been anticipated at the outset, do not fit comfortably with non-directive interviewing as Foote-Whyte's (1982) experiences showed.

Conversation interviewing, the method of choice, allows for a framework to be developed, allowing for flexibility in a controlled manner (Burgess 1982). It also enabled me to come to terms with offering support and advice to participants when required in a similar manner to that first described by Oakley (1981). She suggested that because she was female, women who she interviewed who were entering motherhood, wanted her to share her personal experiences. My interviewing experiences revealed that GPs (male & female) similarly needed to be able to share common experiences, especially if painful and involving the death of a child.
The Case Study Interview Sites

Site One - Northern City Children’s Hospital

Northern City Children’s Hospital is an urban hospital providing regional services to families of children with malignant diseases and non-malignant haematological disorders, often associated with paediatric oncology centres. It is positioned in the centre of a densely populated regional health authority servicing urban, suburban and rural communities. It is one of the larger of the twenty two UKCCSG centres (see Figure 2.1), diagnosing and treating over one hundred new patients annually (UKCCSG 1995). In addition to the children treated from within the regional health authority a small number of children from other, predominantly neighbouring health authorities are treated by the oncology/haematology department at Northern City Children’s Hospital. As well as diagnosing, treating and caring for the families of children with cancer, leukaemia and other associated illnesses, the oncology unit at Northern City Children’s Hospital is responsible for training both doctors and nurses. Junior doctors attached to the unit were either training to pursue a career in paediatric oncology or were attached to a GP training scheme.

The hospital has a team of POONSs which was established with the financial support of CRMF in the early 1990s and funding provision continued to be provided by CRMF at the time of the case study interviews. Since the inception of the team changes in both the structure and staffing have occurred; the team has both expanded in size and has undergone a change of team members. These changes had begun to take place prior to the semi-structured interviews with POONSs during the summer of 1993 resulting in only one of the original team members being interviewed. Although changes in the team structure were incomplete when the case study interviews were conducted approximately twenty one months later, senior hospital-based interviewees who had both witnessed and been affected by the many changes within the Northern City Children’s Hospital Macmillan Paediatric Nursing (MPN) team considered that the MPN service was finally well established; it had continued to provide a stable service for approximately eight months prior to the interviews.
Although one member of the MPN team worked in a slightly different manner to her colleagues due to the differing nature of her work, the remainder of the team divided their work by caseload geographically, dividing the region equally, in a manner common to most regionally-based POONSs. Each team member provided twenty four hour cover to their own terminally ill patients.

The majority of children referred to Northern City Children’s Hospital for diagnosis and treatment by local paediatricians are treated on one of two wards, either the paediatric oncology ward or the bone marrow transplant unit depending on their treatment needs, or in the oncology outpatient department. Children may also be admitted to other wards within the hospital if the oncology ward is full or if children require surgical procedures, usually for the removal of their tumours or for the insertion of CVADs. Children may also require radiotherapy treatment for which they attend another hospital in a neighbouring part of the city.

The MPN team therefore have varying levels of contact with health care professionals within the hospital although most communication occurs between themselves, the two oncology wards and the out-patient department. Interviews with hospital-based health care professionals therefore reflected the differing locations where they worked. In-depth interviews were conducted with staff from the oncology wards, the out-patient department and an out-lying ward where children were admitted for surgery.

Site Two - Southern Regional Hospital
Southern Regional Hospital is based in the leafy outskirts of a large city treating both adults and children. It is a regional children’s cancer treatment centre of average size responsible for treating over sixty children each year (UKCCSG 1995). The hospital like Northern City Children’s Hospital serves urban, suburban and rural communities. Similar also to Northern City Children’s Hospital, it treats a small number of children from neighbouring regional health authorities.
In the paediatric oncology unit at Southern Regional Hospital both the in-patient and out-patient departments, unlike Northern City Children's Hospital, are closely situated. The unit offers facilities for all treatments required by children with malignant disease, including bone marrow transplantation; multi-disciplinary health care professionals, including the POONS team, also have offices housed within the unit. Radiotherapy treatment is offered on the hospital premises, surgical procedures, however, are performed at another nearby hospital. The hospital offers a wide range of post basic nurse training, including certificates, diplomas and degrees all of which are being undertaken by nurses working in the unit. In-depth interviews with hospital-based health care professionals therefore reflected the nature of the unit and the relationships within and were confined to medical, nursing and social work staff working in the paediatric oncology unit.

The POONS service at the hospital was established in the early 1980s and was initially funded by a mixture of both charitable donations and exchequer funding provided by the NHS. It has undergone several alterations since its commencement albeit of a different nature to those seen at Northern City Children's Hospital. Unlike Northern City Children's Hospital however a large amount of anxiety and uncertainty about the future of the service remained at the time the case study interviews were conducted. The concerns related to issues of funding following the establishment of trust status of the hospital and were reflected in the interview data with senior medical and nursing staff (who had themselves recently been subjected to major managerial reorganisation resulting in diminished numbers of senior nursing posts throughout the hospital). The uncertainty of the future direction of the POONS service had temporarily halted the provision of 24 hour cover previously provided to terminally ill children and their families.

Although concerns as to the nature of the POONS service in the future were expressed at the time the interviews were conducted, the existing POONS team continued to be funded from varying sources and divided its work, like the MPN team described above, by geographical location of the patients.
Site Three - Westlands District Hospital

Westlands District Hospital serves the population of the county town of Westlands and its surrounding rural areas and villages within a fifteen to twenty mile radius of the hospital, with a total population of 150,000 (Westlands District Hospital Trust). Sick children from two local health commissions and fund holding GPs are referred by their GPs or admitted through the casualty department with a variety of conditions to the children's department where the ward, the out-patient department and staff offices are situated.

Roughly five new children with malignant disease are seen each year² at Westlands District Hospital paediatric department and are referred to Westcliff Children's Hospital, the region's UKCCSG treatment centre with whom a policy of 'shared care' is operated (see Chapter Two). Unusually, no new children with malignant disease had been seen at the hospital during the last eighteen months to two years. The children's department at Westlands District Hospital is attended by two paediatric consultants and an associate specialist with a particular interest in caring for children with cancer or leukaemia. No registrars are attached to Westlands District Hospital; Senior House Officers are appointed as part of a GP training scheme to care for children on the children's ward, out-patients and the special care baby unit. Limited nurse training is offered by the children's ward and those attached to the ward are undertaking general nurse training. Qualified nurses comprise a mixture of children's trained nurses, general trained nurses and those in the process of undertaking childrens' training.

The children's unit at Westlands District Hospital has benefited from a POONS nursing service since the late 1980s and like many other district-based POONS services, was established with financial backing from CLIC. Typical of other CLIC-funded posts the POONS at Westlands District Hospital offers her services alone although works closely with the paediatric staff at Westlands Hospital and other

²The researcher is grateful to Charles Stiller of the UKCCSG for collating this information specifically for this project.
CLIC-funded POONSs in the region. CLIC nurses aim to provide 24 hour cover to all families caring for children with malignancy, regardless of their disease status. However little evidence arose from interviews with PHCTs to substantiate the existence of this service at Westlands. Hospital-based interviews were conducted with staff from within the paediatric unit.

**Pilot Site - Moorcroft Children’s Hospital**

Moorcroft Children’s Hospital is situated in the centre of a densely populated regional health authority which also serves urban, suburban and rural communities within a radius of approximately eighty miles. It predominantly treats diseases commonly associated with childhood malignancy from within the region but also sees a small number of children from other regional health authorities.

Like Southern Regional Hospital, the paediatric oncology unit at Moorcroft Children’s Hospital benefits from housing in-patients, including bone marrow transplantation facilities, and out-patients in close proximity. Like Northern City Children’s Hospital, it is regarded as one of the larger UKCCSG regional treatment centres. Moorcroft Children’s Hospital has a large commitment to teaching and trains both doctors and nurses in paediatric oncology.

The team of POONSs was established in the mid 1980s with financial assistance provided by a small charity, established specifically to fund POONSs at regional centres. Since the outset of the service the team has undergone changes of funding and of staff with team expansion and replacements. The team is currently funded by the NHS hospital trust. Although recently subjected to changes of staff, the team was highly regarded by those who worked with them and considered very experienced at their work. The POONS team, unlike those at Southern Regional Hospital and the CLIC nurse at Westlands District Hospital do not have an office located within the oncology unit and are instead based some distance from the ward and out-patient areas. Whilst undergoing change within the team, on call provision was temporarily suspended. However the team generally offers a formalised, rotational 24 hour service to families caring for terminally ill children and their carers.
Conclusion

This chapter has discussed the qualitative component to the research. In so doing it has debated the merits of qualitative research, particularly when combined or 'triangulated' with quantitative data. It has also discussed interviews as a constituent of case study research, the data analysis and described the sites selected for inclusion in the three case studies.

Although there are no right or wrong methods or approaches to conducting qualitative research, some methodologies are more appropriate than others, depending on the research questions and the 'intellectual puzzles' to be addressed (e.g. Silverman 1993, Bryman & Burgess 1994, Miles & Huberman 1994, Okely 1994, Coffey & Atkinson 1996, Mason 1996). In this study, as will be demonstrated throughout the remainder of this thesis, combining qualitative methodology - in this instance - individual and/or group focused interviews at selected case study sites, with the quantitative POONS survey has provided a depth to the research which both descriptively and theoretically address the questions underpinning this study.
Chapter Eight - A Descriptive Analysis of the Primary Health Care Teams Case Study Data

Introduction
This chapter is the first of two which draw on qualitative data from the second stage of the research to descriptively portray health care professionals experiences' of working with POONSs. A discussion of the accounts of PHCTs including GPs, DNs, and HVs from the three case study sites is presented here. Chapter Nine depicts the accounts of hospital-based staff who work with POONSs across the three case study sites, including junior hospital doctors and nurses, senior hospital nurses and consultants. The characteristics of PHCTs interviewed during the second stage of the research who are discussed in this chapter are summarised in Table 8.1.

The Accounts of General Practitioners
This section of the chapter highlights common issues which arose for GPs from the case study data. The GPs (n=22) who participated in this study, in common with DNs (n=17) and HVs (n=11), worked in various environments crossing rural, suburban and urban settings. They had either a newly diagnosed or a terminally ill child in their practices whose care was, to a greater or lesser extent, being shared with one of the three hospitals which were the focus of the case studies (see Table 8.1). PHCTs seldom encounter POONS services since they rarely experience caring for children with malignant disease; their accounts concern these unique situations.

Previous Experience of Childhood Malignancy
General practitioners have extensive experience of caring for adults with cancer in the community, particularly those requiring terminal care. In contrast, they have limited experience of childhood malignancy. At most, GPs in this study had previously been involved in the care of one or two other children with malignant disease, either as GPs or as junior hospital doctors; few had previously experienced the death of a child. Limited experience of caring for children with malignant disease is epitomised by one GP who said:
Table 8.1 Interviews conducted with PHCTs at case study sites

<table>
<thead>
<tr>
<th>INTERVIEWEES</th>
<th>Southern Regional area</th>
<th>Westlands District area</th>
<th>Northern City area</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP (newly diagnosed patients)</td>
<td>5</td>
<td>4*</td>
<td>4</td>
<td>24*</td>
</tr>
<tr>
<td>GP (terminal care)</td>
<td>4</td>
<td>3*</td>
<td>4</td>
<td>24*</td>
</tr>
<tr>
<td>HV (depending on child’s age)</td>
<td>5</td>
<td>5</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>DN</td>
<td>8</td>
<td>3</td>
<td>6</td>
<td>17</td>
</tr>
<tr>
<td>TOTAL</td>
<td>22</td>
<td>15*</td>
<td>15</td>
<td>50</td>
</tr>
</tbody>
</table>

* 1 GP included twice since interviewed both in connection with a newly diagnosed child and a terminally ill child
this particular patient was the first one ...in general practice. I’ve not had anyone that’s had a terminal illness. Yes, yes, I’ve not had anyone else
(GP5, Northern City Children’s area)

Relationships with Families, Roles in Diagnosis and Treatment

they (the parents) both happen to be nurses, I know them very well, I looked after Charlotte’s mother through three of her four pregnancies and so I know her very well but I have a very good relationship with all of them (the family)
(GP17, Westlands District area)

Relationships which many GPs develop with families, over time, means that their involvement in the events which led up to a child’s diagnosis was an important time for them. For many, their part in care pre diagnosis, resulted in a child’s referral to the local paediatrician and subsequent transference to the specialist regional centre. This involvement is illustrated by one GP who said:

I actually diagnosed her, not in terms of her histology but in terms of her having something very unpleasant wrong. I actually thought she’d been abused cos she’d got PV bleeding and I got her admitted to the local DGH
(GP13, Northern City area)

A GP’s role pre diagnosis takes on particular significance because it is described in stark contrast to the role which many play once a child’s diagnosis is confirmed. A small number of GPs with well established relationships with families pre diagnosis, suggested that they continued these relationships well into a child’s treatment. Talking of his initial contact with a POONS, one GP epitomises his continued relationship with a family by saying:

[the child’s mother] had already been along to see me by this stage... (when the POONS introduced herself) to bounce ideas and said, ‘they said this at the hospital and I’m not quite sure what they meant’
(GP12, Northern City area)
For most however, confirmation of a child’s diagnosis at the regional centre and subsequent treatment, is a period in which a child’s care is ‘taken out of their hands’. Whilst some GPs would have preferred to have greater input and some indeed went out of their way to pursue active roles such as monitoring blood results, most recognised that specialised care was required to treat childhood malignancy. This care is generally considered to exclude their own professional input and to be in the best interests of the child, the family and the treatment.

Communication Difficulties Across the Hospital/Community Divide

Whilst recognising the need for specialised care, GPs, for the most part, still feel a need to be kept informed of a child’s and family’s progress. General practitioners frequently encounter difficulties in obtaining information from hospital consultants, regardless of specialty or hospital. With reference to the child with malignant disease, GPs considered that they experienced delays in receiving letters about the diagnosis, investigations and treatment or information regarding any role which they might be required to play. Furthermore, this problem was exacerbated when GPs experienced difficulties locating hospital medical staff by ’phone. However, for a small number of GPs this problem was eased by informal, social networks with local paediatric consultants. Some analogies were drawn between the difficulties in obtaining relevant and useful information from all hospital consultants and the consultants treating the children in question. Nevertheless, the nature of childhood cancer treatment instilled in many GPs a feeling of needing to gain more regular information from paediatric oncology consultants than from other consultants treating adults. In spite of this, once received, written information from consultants was frequently viewed by GPs to be too technical and beyond their comprehension. One illustrated this by saying:

*there were letters coming through... but the details of the chemotherapy are a little bit sort of advanced for me*

(GP16, Westlands District area)
Introduction to POONSs

GPs see POONSs as vital links between the hospital and the community. Limited prior experience of caring for children with malignant disease, long-established relationships with families and difficulties obtaining and understanding written correspondence from hospital consultants, means that POONSs are welcomed by most GPs. However, the ways in which POONSs introduce themselves to GPs vary. The spectrum depends on both the health status of the child and the case study site to which both child and GP are attached. At one end of the continuum, GPs had no contact with POONSs, although they were usually aware that children were being visited at home by a nurse from the hospital. This was particularly so for GPs in the Westlands vicinity who were aware of CLIC’s high profile in the area. At the other end of the continuum, GPs had had a great deal of contact with POONSs, working closely with them. This was particularly the case for GPs caring for terminally ill children whose care was being co-ordinated by regional POONSs. Half way along this continuum of contact, are GPs with newly diagnosed children in their practice who received communication from POONSs shortly after confirmation of a child’s diagnosis. These GPs generally deemed further contact with POONSs unnecessary whilst children remained well although appreciated the contact they had had with POONSs. Communication differences between POONSs and GPs are developed further in Chapter Eleven.

A typical example of early communication, halfway along this continuum of introduction to POONSs, is given by a GP from the Southern Regional area. He talked favourably about a visit he received from a POONS shortly after a child’s diagnosis had been confirmed. He reflected on how he had been telephoned by the POONS and on the visit which followed. He also talked of the valuable information he, the DN and the HV had been given about the child’s Hickman line and other aspects of the child’s care which might have had implications for the PHCT. This information was valued since such treatment and hands-on care was previously unfamiliar to him and other members of the team. Verbal information had also been backed up with written information which offered reassurance, acting as an ‘aide memoire’ for future reference. He said:
[POONS 1] did actually come here once to speak to all of us who might be involved, you know, in case we had any kind of problems with his Hickman lines and that sort of thing. She left us with literature about the care of the Hickman lines and with details of the actual chemotherapy regime that he was having

(GP9, Southern Regional area)

Childrens’ Specialised Needs

Hickman line management, in general, is perceived to be highly unusual in community settings, necessitating specialised care. For most GPs, such as the one above, its specialised nature becomes demystified when they are incorporated into the care, being shown how to dress, heparinise1, administer drugs and/or withdraw blood samples from the line. A few however, are not offered such opportunities, remaining uninvolved in care. This means that such tasks remain specialised, awesome and the domain of POONSs. Another particularly specialist area which arouses concern amongst GPs involves terminal care. Specifically, this pertains to pain and symptom control and issues around the death of a child. With one exception, GPs with a recently diagnosed child in their practice had no experience of working with POONSs during a child’s terminal illness. A few however, recalled previous unpleasant experiences when, without the support of POONSs, children had either died uncomfortably at home or, against families’ wishes but due to poorly controlled pain, had died in hospital. Other GPs, with no experience of caring for dying children generally feared the prospect. This is exemplified by one who said:

*I’ve never actually been involved in the terminal care of a child with cancer. I think it’s something that I would probably find very daunting and quite frightening in the sense of feeling my own ignorance to be able to care and help*

(GP19, Southern Regional area)

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1 Hickman lines need regularly flushing with a dilution of the anti-coagulant, Heparin, to maintain patency.
In general, GPs who had recently experienced the death of a child in their practice and had benefitted from the professional support of POONSs either: (1) recognised the professional support and expertise they received from POONSs. This enabled better pain control to be achieved than would have occurred had POONSs not been able to offer this advice. This advice thereby ensured that the child had a comfortable and peaceful death. (2) Felt that pain control would have been achieved without the services of POONSs but was nevertheless facilitated by their advice or (3) expressed concerns that children died in pain. This occurred because the GPs concerned were unsure how to respond to a child's needs and felt unsupported by the hospital, particularly at night when the POONS service, they believed, was unavailable to them. This is reflected by one GP who said:

the last night.. I was in there something like 10 o'clock, 11 o'clock, 2 o'clock, 4 o'clock, 6 o'clock and at the end I was using morphine to make her comfortable, she was in agony you know  

(GP5, Westlands District area)

and another who commented:

his demands, his needs, his terrors, his fears - I think at the end of the day he struggled to remain alive. A lot of it was - towards the end there was pain relief. A lot of that I think, his pain was his anxieties, his fears 

(GP6, Westlands District area)

Co-Ordinating Patient Care

GPs recognise that terminal care is a time when the greater part of a child's care is provided in the community. For most, a large part of this care is viewed to be the domain of community staff, shared particularly between GPs and DNs. For those GPs who had played a part in providing terminal care to children, co-ordination of care was imperative. Most GPs who had worked with POONSs during a child's terminal illness, felt that POONSs co-ordinated children's care in the community. However, this co-ordination differs. General practitioners working with POONSs at regional centres talked of POONSs leading a team of health care professionals usually including the POONS, the GP and the DN. This team was initiated by POONSs at
the outset of a child's terminal illness as meetings were set up by POONSs at health centres to plan care. The experiences of GPs in the Westlands area however, differed. For these GPs, terminal care in common with other components of care, they felt, was determined by the hospital and co-ordinated by POONSs at home. They recognised like other GPs that terminal care involved close teamwork. However most acknowledged that they were not major contributors to the terminal care team and often only acted upon instructions from the hospital or POONS. These instructions frequently concerned writing prescriptions for drugs required to control a child's symptoms. Whatever type of patient care co-ordination was experienced by GPs all appreciated and were reassured by the presence of POONS services.

POONSs' Relationships with Families

Families are seen to develop especially close relationships with POONSs and POONSs with families. These relationships becomes ‘special’ despite the lengthy relationships some GPs had established with families prior to a child’s diagnosis being made. They arise from the amount of time which POONSs are perceived to be able to dedicate to families, particularly during a child’s terminal illness, their abilities to boundary hop between the community and the hospital and the greater knowledge which POONSs possess, enabling them to better support families at home. The emotional trauma experienced by parents when their child is first diagnosed with a malignant disease and the dependence some families develop on the hospital during their child’s treatment, are the foundations on which these ‘special’ relationships develop. A subsequent terminal illness, is perceived to strengthen existing bonds between families and POONSs. Furthermore, POONSs are seen to have the ability to develop these relationships with the family as a whole, not just with individual family members. The ‘special’ relationships which families develop with POONSs and POONSs with families are also highlighted by DNs and HVs. They are epitomised by two GPs who commented:

*she spent a lot more time with the family, she was very much a family person as I think I became but she was more so because she’d been involved right from the beginning*

(GP4, Northern City area)
I know she was a great support to the family... I know she had a close relationship with the family that they very much appreciated

(GP7, Westlands District area)

POONSs’ Personalities

In common with DNs and HVs, some GPs had the opportunity to get to know something of the POONS they worked with. For these GPs and other PHCT members, POONSs’ personalities play an important part in forging relationships between them and most found the personality of the POONS they worked with noteworthy. As one GP commented:

she was just very pleasant, you could get on with her, she was quite a deep person whose personality was quite caring, quite sensitive... she was just easy to get on with

(GP4, Northern City area)

Recapitulating, this section highlights some common issues discussed amongst GPs. It emphasises the unique situation a GP faces when a child in his/her practice is diagnosed with malignant disease. It describes the roles which GPs feel they play prior to a child’s diagnosis, in the light of the long standing relationships many develop with families. In addition, it discusses their roles during a child’s treatment and for some, during a terminal illness. This section of the chapter also illustrates how GPs first became acquainted with POONSs and the subsequent roles POONSs played in their professional lives. It suggests, regardless of their degree of contact, GPs generally welcome POONSs’ interventions; POONSs’ personalities were also seen as an important feature of the whole relationship and service.

District Nurses’ Stories

The point of decline in a child’s health, if or when s/he moves from being well to being terminally ill, is poignant to a district nurse’s role in caring for the child with cancer and his/her family and to forging relationships with POONSs. This is a time when DNs may first encounter a child with malignant disease and their family and, for many, may be one of the few times when they are required to provide nursing care to a sick child. A small number of DNs in this study had however, been
introduced to families at an early stage in a child’s ‘cancer journey’. Nevertheless, whilst appreciating this early contact with families, DNs recognise that their professional role at this time is often limited or poorly defined. Terminal care however, marks a time when a more distinct role is apparent. District nurses’ limited prior encounters with sick children in general, moulded not only their perceptions of their role in caring for a child dying from malignant disease, but also their relationships with POONSs. The DNs interviewed in this study (n=17) are outlined in Table 8.1.

The moment at which DNs become involved in a child’s terminal care is marked by several features. For some, it is inaugurated by an interdisciplinary case conference held at the health centre, initiated by POONSs, at which the DN’s potential role is mapped out. For others, it is marked by ‘stepping up’ previously erratic and infrequent visits to a family already in their acquaintance. For several, it engenders a period of stress in their professional lives as they are required to provide nursing care to a client group with which they are unfamiliar, lacking the knowledge and skills required to provide specialised nursing care. For a small number, it marks a period of uncertainty about how to fit into an already established professional support network, predominantly provided by hospital-based staff and led by POONSs.

The Case Conference
For most DNs, their point of entry into a family’s care is initiated through a case conference or practice meeting, where POONSs, DNs, GPs and others such as HVs or school nurses come together to discuss and plan the care it is anticipated may be required during a child’s terminal illness. Planning care in this way is facilitated by POONSs whose knowledge and prior encounters with dying children are drawn upon to illustrate likely scenarios. This is a time for forging relationships between DNs and POONSs. It is an event which DNs hold in high esteem both for establishing communication links with POONSs and for gaining insight into the disease, past treatment, symptom management and the dynamics and coping mechanisms of the various families in their care. For the few DNs who were not invited to attend such meetings, such an initiative was missed and would have been seen as a resolution to
some of the communication problems which subsequently developed both between DNs and POONSs and DNs and the families they cared for. As one DN who had not been invited to discussions about the patient in her care said:

*I think we need(ed) more liaison maybe being there at practice meetings when, you know, GPs and district nurses come together, perhaps coming along from time to time*

(DN8, Westlands District area)

Limited experience of nursing sick children brings about great anxiety for most DNs when referred a terminally ill child. For those previously unacquainted with the child and family, fear is produced when contemplating the first meeting with a family. For the most part, anxiety arises when considering their own emotions concerning the death of a child. For most DNs however, their anxiety is lessened by their introduction to and working alongside POONSs and by being given insight into families’ dynamics before meeting them. Hence, emotional strength was gained by DNs who attended case conferences. For some, POONSs’ offers to accompany DNs on their initial visits aided further reduction in their anxiety, whilst for one DN in the Westlands area, anxiety was relieved on learning that the POONS would provide most of the required nursing care.

‘Stepping Up’ Visits

For DNs who had developed relationships with families prior to a child’s terminal illness, the point of decline in a child’s health marked a ‘stepping up’ of visits and a more clearly defined role. Equally, when DNs make the acquaintance of newly diagnosed children and their families, terminal care is viewed as a time when acquaintances with families would need to be renewed. Previously established relationships with a family whose acquaintance was renewed when a child became terminally ill, is epitomised by one DN who had first visited the family in her care three years previously. Inheriting the case from her predecessor she provided emotional support to the mother. However, she felt that she did not possess the knowledge or skills to provide the care required of her or the understanding to cater for the mother’s needs. Furthermore, it was considered that the school nurse was
appropriately providing family support. However, when the child’s disease returned her visits were ‘stepped up’ because hands-on nursing skills would now potentially be required. She commented:

*we had a case conference about the little girl... she’d got lymphoedema in her legs and ... we were going to be involved in bandaging her legs*

(DN2, Northern City area)

**Co-Ordinating Visits**

A case conference at the outset of a child’s terminal illness is pivotal to the subsequent relationships DNs form with both POONSs and families. Planning care ensures that DNs understand their role within the interdisciplinary team and co-ordination of patient visits between POONSs and DNs is established at this time. This point is illustrated by one DN visiting a dying child whose parents were reluctant to accept her professional support. She said:

*she (the POONS) used to 'phone me up... on a fairly regular basis and keep me informed of what was going on - and I went when she suggested we went, I really left it with her*

(DN10, Southern Regional area)

Frequent and regular contact between POONSs and DNs thus evolves from this point from which much is learnt by DNs from POONSs. The case conference also ensures that DNs know how to contact POONSs or their covering services so they can regularly exchange information or obtain advice in more urgent circumstances. They are also able to corroborate, passing the same information to families as POONSs:

*a little pact was made between us (the parents, the POONS and myself) about who says what and who does what before we go upstairs (to see the child)*

(DN9, Southern Regional area)
In contrast, when DNs are not invited to care planning meetings, their roles are uncertain, communication between DNs and POONSs is limited and difficult to establish and visits between DNs and POONSs are unco-ordinated. Furthermore, relationships between DNs and families are poorly developed. One DN nursing an adolescent reflected:

really to have given him the support that he needed I needed to build up a relationship. It was very, very hard - he was so young and he tried so hard and he was so independent but he had built up a relationship with [district POONS] but she wasn't giving the care... and yet his relationship he felt was with her

(DN7, Westlands District area)

Specialist Practice
Like GPs, DNs are unfamiliar with CVADs and symptom control during a child’s terminal care, perceiving both to be specialised areas of practice. In particular, familiar drugs administered via unfamiliar routes such as morphine infused intravenously, morphine sulphate tablets administered rectally and drugs to reduce nausea and/or vomiting administered via skin patches, are considered highly unusual in the day-to-day practices of DNs. In addition, talking to children, either patients or siblings, about illness and death is frequently perceived to be a specialised area of nursing in which DNs feel out of their depth. District nurses who develop close working relationships with POONSs learn much about symptom management of terminally ill children and gain confidence to participate in their care. In contrast, those with little or no contact with POONSs learn little, such skills remaining the province of POONSs.

Parents’ Superior Knowledge and Skills
It has earlier been contended that DNs lack the skills required to care for children with malignant disease and their families. Compounding this, DNs believe parents and older children possess greater skills and knowledge than themselves. Not only do parents and children possess greater knowledge, but they frequently acquire the abilities to perform practical nursing skills which DNs lack. These two points are best illustrated by two DNs who said:
(the patient) was probably more competent at doing it (Hickman line care) than me because he'd actually done it on himself
(DN7, Westlands District area)

the family were very open about her illness. They went through everything with me from start to finish because they were knowledgable about it and I probably learnt a lot more from the family
(DN2, Northern City area)

The greater knowledge possessed by both children and parents becomes problematic for DNs only if they lack professional support from POONSs. Most are prepared to overtly acknowledge families' greater expertise and learn from the families they work with.

In summary, this section highlights issues discussed amongst DNs. It suggests that DNs usually encounter children with malignant disease only when they are referred to them, mostly by POONSs, and that when children are referred to DNs they more commonly provide nursing care to dying children than those who are newly diagnosed. The rarity of this event brings about undue stress. District nurses' anxieties are lessened through early meetings with POONSs in which any care they may be required to provide is discussed before meeting the family. However, for those who did not meet regularly with a POONS, their roles remained unclear and their relationships with families poorly defined. The continued support which most DNs receive from POONSs throughout a child's terminal illness is facilitated by regularly co-ordinating and discussing their visits to families with POONSs. Continuing communication with POONSs enables DNs to participate in a family's care during which time much is learnt not only from POONSs but also from families.

Health Visitors' Accounts
Health visitors' (n=11) professional experiences differ from both GPs and DNs. Used to working with the under fives, they occasionally encounter life-threatened or life-limited children and their families. Furthermore, it is not uncommon for them to work with families who experience a bereavement from cot death or another cause. In addition, a few HVs in this study had worked in Third World countries where the
death of a child is more common than in the Western World. One HV had previously been a paediatric ward sister at the local hospital where there was shared care with the affiliated regional centre; others had previously met children with malignant disease and their families, either as HVs or as hospital-based nurses many years previously. However, all these experiences are limited. These limited experiences are the foundations on which HVs' perceptions and attitudes towards POONS work are grounded. The HVs who participated in this study are outlined in Table 8.1.

**Families: Relationships Before and During the Illness**

Like GPs, many HVs have long-established relationships with families prior to a child’s diagnosis. These relationships vary according to the numbers of children within families and consequential involvement in a mother’s antenatal care, childrens’ immunizations and developmental checks. The nature of relationships with families is also determined by the existence of social problems within a family and by the length of time spent in their current posts. Extensive work histories in their current positions led most HVs to consider that they had in-depth insight into a family’s dynamics. A few recognised the difficulties some parents had in coming to terms with a child’s diagnosis or the anger they expressed if a perceived delay occurred in making the diagnosis. Some HVs, like GPs, even felt responsible for assisting in the detection of a child’s illness. One commented:

*she (the child) came for a developmental assessment .... and it was [GP] and I that were doing the developmental assessment and I did the bit where you test their skills and [GP] was doing a medical examination and he listened to Rachael's heart ... by some quirk I think she had a chest X-ray ... and when they'd done the chest X-ray they found the tumour*

(HV1, Moorcroft Children’s area)

Frequent and regular admissions to hospital ensure that HVs sometimes have difficulty maintaining contact with families during a child’s chemotherapy treatment. Not knowing whether children are in hospital or at home, for some HVs, is frustrating; they feel concern for other family members, particularly if problems unrelated to the child’s diagnosis exist for other siblings, and a responsibility to visit families at home between hospital admissions. In addition, without having up-to-date
relevant information, whilst being able to listen, HVs find it difficult to answer a mother’s questions appropriately. Although a few talked to mothers on the telephone, wrote to them whilst their children were in hospital or were able to glean information from mothers between hospital visits, several HVs relied on families’ friends and neighbours to inform them of a family’s whereabouts. For most HVs, supporting mothers at this time is also hampered by increased pressures of work and changing HV roles necessitating more paper work. Difficulties maintaining contact with families during treatment is epitomised by one HV who said:

he (the child) went up to (a specialist children’s hospital) as a day case. He had to have an echo-cardiogram. I’m not sure if he didn’t have it the first time or if it’s a repeat one cos he went up the week before, so I haven’t actually talked to him yet

(HV 10, Southern Regional area)

By contrast, other HVs, acknowledging that children were responding well to their chemotherapy and regularly attending school, or that parents were gaining emotional support from a wide social circle of friends and/or family, or that mothers were confidently managing their child’s physical care (usually Hickman lines), considered that families required little input from themselves between treatments. In addition, in the knowledge that families were receiving visits at home from POONSs, it was recognised by several HVs that it is not always in a family’s best interests to receive numerous visits from too many, varied health care professionals, and so they felt it pertinent to take a back step. Whether happy to take a back step, satisfied with their own degree of professional support or frustrated with not being able to keep track of families, most HVs recognised that children and their families were well supported by hospital-based staff, most particularly by POONSs.

During a child’s terminal illness, HVs recognise that they are not key players and that ‘specialised’ hands-on care may be required. District nurses, GPs and sometimes palliative care nurses, they suggest, are more appropriate members of the PHCT than themselves to participate in a child’s and family’s care at this time. Viewing their own roles as supportive, whilst being able to listen to families, they generally
consider the emotional support required necessitates inside, 'specialist' knowledge to say the right things, which they lack. Hence, most HVs consider it appropriate to maintain a low profile during terminal illness. One HV describes this when she said:

*it's important to recognise that if a family is getting the help and support from particular professionals - I think too many people meddling can create more problems - so I didn't get involved*

(HV9, Westlands District area)

**Encountering POONSs**

Limited roles both at the outset of a child's 'cancer journey' and during terminal care, mean that HVs feel that POONSs play a significant part in families’ lives during these times. At the onset of a child's disease, POONSs may also be important to HVs because it is from POONSs, as well as families, that they glean information about a child's disease, prognosis and treatment. Relationships developed with POONSs at these times are, in part, dependent upon previous encounters between them. HVs within the Westlands vicinity, like GPs, are acquainted with the concept and high profile of CLIC nursing services and so were aware of the presence of the POONS in their area, regardless of any contact with her. In addition, several had been acquainted with the CLIC nurse at Westlands whilst she had been the ward sister to the children's ward. Most HVs therefore, had previously worked with the POONS at Westlands in one capacity or another. Prior knowledge of POONSs was also evident in the Southern Regional area - not only had several HVs had prior contact with the POONS nursing service at the Southern, but they had also worked with POONSs from Moorcroft Children's which, in part, shares the same regional catchment area.

Health visitors’ encounters with POONSs are varied. Some in this study had never or seldom met a POONS, found ‘their’ POONS difficult to obtain, felt subtly elbowed out of supporting families by a POONS or expressed curiosity at having referred back to them children, now over five, whom they had previously provided HV services to. One even went so far as to say that she found the POONS she worked with unable to adapt to a family’s needs, traumatising them. By contrast, others found POONSs
helpful, supportive, always easy to access on the telephone and maintained contact with them throughout a child’s treatment. These HVs had generally initially met at a practice meeting or case conference in which information relevant to their own professional needs e.g. immunization requirements, was imparted; they conducted joint visits to families’ homes with POONSs and/or, through gaining insight into a child’s condition, they acquired confidence in their abilities to visit families following a child’s diagnosis. A particularly close working relationship with POONSs is demonstrated by a HV who had worked with POONSs from both the Southern and Moorcroft. She said:

[POONS 1] did come down once he was diagnosed and tell us, the GP, the district nurse and myself (about the Hickman line)... it was very helpful and [POONS 1] did liaise with me if there were problems... I used [POONS 3] a lot more.. I think for me, as much as anyone to off load onto... she would come down from Moorcroft with information and ideas.. I used her a lot and we rang each other a lot

(HV 3, Southern Regional area)

Whatever their encounters, whilst appreciating the availability of POONSs, most HVs would have preferred more information. In particular, they were keen to be notified by POONSs each time a child was discharged from hospital following treatment. This, they felt, would ensure that they did not always have to depend on mothers to inform them of a child’s progress.

This section describes issues arising for HVs when they (a) encounter a child with malignant disease and their families and (b) brush with POONSs. It suggests that whilst HVs may have long standing relationships with families, when a child is first diagnosed with a malignant disease or is terminally ill, they view POONSs as the key workers. For the most part, they happily remain in the background until treatment is established or parents bereaved. However, HVs would prefer, whilst children are receiving treatment, to be kept more informed of a child’s and family’s progress.
Conclusion
This chapter examines qualitative data from the second stage of the research to descriptively portray PHCTs’ experiences when they unusually encounter a child with a malignant disease and subsequently work with a POONS. General practitioners and HVs often have long-established relationships with families which are impinged upon by a child’s diagnosis. At this point hospital-based support steps in and POONSs are seen to develop intimate relationships with families. For some primary health care (PHC) professionals links are formed with POONSs at this time. Relationships between families and POONSs are strengthened if a child becomes terminally ill. Paediatric palliative care is highly unusual in the day-to-day practices of PHCTs and this chapter describes the professional bonds which may be formed and/or intensified between POONSs and PHCTs at this time. District nurses in particular may become acquainted with families during this period. For most PHC professionals, POONSs are welcomed at all times. However, they are particularly valued during terminal illness when highly specialised community-based care is required. The narratives of GPs, HVs and DNs recounted here are built upon in subsequent chapters. Firstly, in Chapter Ten, along with data from the POONS survey, the experiences of those working with POONSs are drawn upon to discuss ‘specialist’ knowledge. Secondly, in Chapter Eleven, they are drawn upon to develop a relationship typology between POONSs and PHCTs.
Chapter Nine - A Descriptive Analysis of the Hospital-Based Health Care Professionals Case Study Data

Introduction
In common with Chapter Eight, this chapter also draws on qualitative data from the second stage of the research to descriptively portray health care professionals' experiences of working with POONSs. The previous chapter addressed PHCTs' experiences. Here, the accounts of hospital-based health care professionals including junior hospital doctors and nurses, senior hospital nurses and consultants are discussed. The attributes of hospital-based staff who participated in the case studies are summed up in Table 9.1.

Staff Nurses' Stories
The professional backgrounds and experiences of hospital-based junior SNs (n=15) differ. In particular, they vary between working at regional centres where hospital-based health care professionals, including junior SNs, specifically provide care to children with malignant disease and their families, and working at a DGH. At Westlands District Hospital, staff, and particularly junior SNs, infrequently encounter a child with a malignant disease; when they do, nursing care is provided by the POONS or senior nursing staff rather than junior SNs. Instead, SNs nurse sick children with a variety of medical and surgical conditions which relieves the anxiety they otherwise experience when nursing children with malignant disease. In addition, the length of time working on the units in which SNs in this study were employed varied. These varied backgrounds and experiences influenced a range of views amongst SNs concerning the work of POONSs. Issues common to all those interviewed are presented here. Staff nurses who participated in the study (including the pilot site at Moorcroft Children's Hospital) are outlined in Table 9.1.
Table 9.1 Interviews conducted with hospital-based health care professionals at case study and pilot sites

<table>
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<th>Northern City Hospital</th>
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<tr>
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</table>
Making the Acquaintance of POONSs

Staff nurses become acquainted with POONSs in a variety of ways. Becoming familiar with the POONS at Westlands was an evolutionary process since both the POONS and the ‘junior’ SNs had worked together for many years. For some, this included the period in which the POONS had previously been the ward sister. Others had previously, permanently worked on night duty for many years and had only more recently become familiar with the POONS after altering their work patterns to day shifts. Whatever their prior relationships, SNs at Westlands had never formally been introduced to the work of a POONS, they had little day-to-day contact with the POONS they worked with and lacked insight into her work in the community. One SN who had worked on the ward for many years as an EN before undertaking RSCN training commented:

*For a few years, other than passing her in the ward, I didn’t really have a lot to do with her*

(SN6, Westlands District Hospital)

In contrast, SNs at regional centres had generally been appointed to their posts within the last year; they had mostly had formal introductions to POONSs either though induction programmes, courses, lectures or written hand-outs. These introductions detailed POONSs’ roles, giving SNs insight into that work. This insight is furthered when SNs are given the opportunity, by POONSs, to visit families in their own home and PHCTs. One SN talking of her introduction to POONSs commented:

*I met them - I took a post here in February - at lectures. We were introduced on an induction course. We had a session where they explained their role... I’ve heard each member (of the POONS team) speak about some topic or other*

(SN2, Moorcroft Children’s Hospital)

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1 The SNs at Westlands who participated in this study were deemed to be ‘junior’ both by themselves and the ward sister. Although all but one had recently attained the RSCN qualification moving them along the ladder of seniority, they were still deemed ‘junior’ since they had minimal experience (exacerbated by the dearth of patients during the preceding two years) of nursing children with malignant disease. In reality all had worked on the ward for many years.
The Focus of POONS Work

POONSs provide a link between primary, secondary and tertiary care. How these links are provided by POONSs however, vary. Staff nurses at regional centres consider that POONSs provide links between the regional centre and local communities. Here, families are supported by and health care professionals are taught by POONSs to be providers of care, during periods when children are either in their local hospitals or at home. A POONS's working world is therefore away from the confines of the regional centre. Staff nurses at Westlands on the other hand, believe that a POONS places equal emphasis on caring for children in hospital as she does in the community, following a family wherever care is required. Furthermore, a POONS’s main links with other health care professionals lie with the regional centre at Westcliff Children's, not with PHCTs. PHCTs derive benefit from POONSs through being excluded from care. Exemplifying this, one SN considered:

district nurses are very worried about having to cope with a child at home, quite understandably, so.. I would have thought they’d have been quite grateful to have [district POONS] to do it

(SN6, Westlands District Hospital)

Hospital-based nursing, by regional POONSs, is minimal and predominantly concerns meeting and talking with newly diagnosed children and their families and planning their discharge from hospital, and exchanging information about patients and their families with staff. Whether regional or district-based, the nature of POONSs work means that most SNs have minimal contact with POONSs; they seldom see POONSs and rarely talk to them. Instead, communication about patient care occurs more usually between senior nursing staff and POONSs, sometimes on a notice board or on paper. One SN remarked:

we use a communication book. If there's been any unpleasant things happening at home, where a child’s died or the family aren't coping, they always write in the communication book. That seems to be the liaison

(SN10, Southern Regional Hospital)
Unusually however, SNs at Moorcroft Children's derived great benefit from POONSs and had regular contact with them. In the main, they valued POONSs' knowledge of managing symptoms during a child’s terminal illness. Although it was acknowledged that few children died in hospital, when a terminally ill child was cared for on the ward, SNs drew heavily on POONSs’ expertise which required much two-way communication. Compounding this, POONSs were regularly called upon by ward and OPD-based SNs to discuss a child’s discharge. Regular contact with POONSs in such situations means that SNs find POONSs very easy to contact by 'phone when they are not on the ward.

Despite little contact between POONSs and most SNs, at regional centres POONSs generally supplement the work of SNs. In particular, POONSs provide psycho-social care to families whilst in hospital which can be continued at home or in a child’s local hospital after discharge from the treatment centre. Staff nurses do not have the time to provide psycho-social care on wards and they are generally grateful that POONSs are able to give families the support they require. POONSs also supplement SNs’ work because care which they instigate and have often begun to teach parents, may be continued by POONSs when families are discharged from hospital. This differs from Westlands, where the POONS provides care to children and their families on the ward which would otherwise be provided by ward staff. As one SN said:

*I suppose (if) she’s not there we would be doing the temperature and things like that*

(SN8, Westlands District Hospital)

Relationships with Families

Relationships which SNs form with families vary. SNs at Westlands rarely acquire an opportunity to become close to children with cancer and their families because they seldom come into contact with them. Staff nurses at regional centres on the other hand, particularly those working in OPDs or long-stay wards such as BMT units, gain a wealth of opportunity to develop sustaining relationships with families. However close SNs may become to particular children and their families, the relationships which families develop with POONSs are deemed to be closer and more long-term.
SNs who become close to families see themselves being concerned with the day-to-day, hands-on management of a child's care. This, they feel, only provides them with 'snap-shots' of families' dynamics. Unlike themselves, POONSs are in a position to allot 'quality time' to families, both whilst on the ward and at home. Being able to spend time with families in both locations enables POONSs to delve deeply into families' feelings. Wherever their work location, POONSs develop 'global' relationships with families, enabling them to focus holistically on the needs of the whole family. Whilst some SNs were envious of the amount of time POONSs are able to dedicate to individual families, most felt that families derive benefit from the time POONSs are able to give, which they themselves are unable to do. One SN commented:

*I found a lot of parents could talk a lot better when they were outside the hospital, they could share like with [POONS 1] and she got into more depth, got more sort of in-depth knowledge into how they were feeling and more supported when they were out in the community*

(SN11, Southern Regional Hospital)

**The Expertise of POONSs**

Sisters' responsibilities differ from POONSs - sisters are concerned with managing nurses, whilst POONSs generally manage patients. More importantly, sisters act as mentors, holding authority over SNs. POONSs in contrast are more autonomous and detached from the day-to-day running of the wards and OPD. These factors, coupled with the work history of the Westlands POONS, ensured that the POONS here was seen to be more senior than the ward sister. For most SNs however, POONSs hold equal status to sisters - their skills are 'just different'. The expertise of the POONS at Westlands lay in her lengthy experience in paediatric nursing and her ability to perform 'specialist' nursing tasks such as Hickman line care. For those at regional centres however, expertise was derived from experience in paediatric oncology and through the community, giving POONSs a wisdom in palliative and shared care not possessed by other members of staff. Furthermore, wherever the location, the nature of POONSs' work is recognised to require particular personality traits. These include the ability to make decisions and be organised, to be confident, to possess good
communication skills which facilitate ambassadorial roles or to have an aptitude for the work.

In summary, this section discusses issues common amongst SNs. It describes their own varying work histories and the parts these have played in forming relationships with POONSs. It depicts the various ways in which SNs came to be acquainted with POONSs and the relationships they have subsequently formed with POONSs. Furthermore, this section portrays the relationships which SNs develop with families and the ways these relationships differ from those developed between POONSs and families. Lastly, it highlights the factors which, for SNs, constitute POONSs' expertise and how POONSs' expertise differs from sisters.

**The Accounts of Junior Hospital Doctors**

Junior hospital doctors\(^2\) work on the wards, in OPDs, and in the case of Westlands - on the Special Care Baby Unit and in the Accident and Emergency department. Contact between POONSs and SHOs \((n=6)\) is affected by these differing work locations. However across these locations, relationships between POONSs and SHOs also vary between hospitals. Consequently, SHOs' experiences of working with POONSs differed widely. Their experiences ranged from those who had not formally been introduced to POONSs and encountering them only rarely to those who had frequent and regular communication with POONSs, working closely with them. Issues common to each of the SHOs in this study are discussed here and participants are summarised in Table 9.1.

**Working with POONSs**

The experiences of working with POONSs differ. For some SHOs frequent contact with POONSs exists. For others however, there is minimal communication with POONSs. At the Southern for example, junior doctors who worked in the OPD and planned the care of children attending clinics, regularly talked to POONSs about

\(^2\) For simplicity, all junior doctors in this study are referred to as Senior House Officers (SHO). A small number however were junior registrars.
children who shared care between the hospital and local communities. Here, there was a need to obtain or exchange information with POONSs about care provided by local health care professionals. This included results of blood tests, a child’s response to a recent course of chemotherapy treatment or psycho-social issues. Similarly, terminal care brought POONSs and some ward-based junior doctors at the Southern together. Since no out-of-hours cover was provided by POONSs at night or at weekends, families and PHCTs depended on junior doctors for advice during these times. This necessitates close liaison between POONSs and junior doctors (who feel inexperienced in palliative care) as POONSs ‘hand over’ children, families and PHCTs who they anticipate may require ‘specialist’ advice. Closer relationships between POONSs and ward-based SHOs existed at Moorcroft. Here, through a comprehensive induction course, SHOs met POONSs at the outset of their appointments and gained insight into their work. Furthermore, POONSs were recognised as experts in symptom management and advice about children in hospital was regularly sought by SHOs, from POONSs, in this area. These points are epitomised by two SHOs who commented:

**(in OPD) we liaised with the community nurses quite closely because, as outpatient’s [junior doctor] you go to a lot of trouble shooting from parents and from other hospitals which overlaps with [POONS 1’s] and [POONS 2’s] role**

**(SHO5, Southern Regional Hospital)**

*I find them very useful and I know that I can ask them really any day you know, should I have a problem*

**(SHO3, Moorcroft Children’s Hospital)**

In contrast, other ward-based SHOs at the Southern along with those at the Northern and Westlands, generally had little contact with POONSs. For those at regional centres who had minimal communication with POONSs, contact was usually limited to the regular multi-disciplinary ward rounds when POONSs discuss children they visit at home. These children are seldom known to SHOs and the imparted information has little relevance to their day-to-day work. Furthermore, little insight is gained by some SHOs into the work of POONSs. Limited contact between SHOs and POONSs is illustrated by a junior doctor who said:

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we've really only come across them in the twice weekly ward round

(SHO1, Northern City Children's)

Although a current dearth of patients hampered communication between the POONS at Westlands and SHOs, other than passing in the corridor, SHOs generally had no contact with POONSs. When they did, contact more usually concerned task delegation. One SHO who worked at Westlands recounting his professional meetings with the POONS commented:

...twice - she's just told me there's patients coming in for blood tests the next day

(SHO2, Westlands District Hospital)

Differences Between POONSs and Other Health Care Professionals

Junior hospital doctors see POONSs as senior members of the nursing staff. Like all senior nurses, POONSs have a wealth of experience and knowledge exceeding SHOs. POONSs' knowledge differs from, and for a small number of SHOs, exceeds that acquired by both sisters and community nurses. Junior doctors at Moorcroft drew heavily on this expertise, learnt much from POONSs: 'we weren't sure what sort of pain relief to give because the baby was only four months old... [POONS 3] knew the dosages and what's effective and what's not' (SH04, Moorcroft Children's), and held them in higher esteem than sisters. However for other SHOs at regional centres, the community and palliative care focus of POONSs' work had little relevance to the more acute emphasis placed upon their own hospital-based care. In this situation, SHOs learnt more from senior SNs and ward sisters than from POONSs.

Irrespective of work location, SHOs consider their work and that of other hospital-based colleagues possesses a 'day-to-dayness'. In contrast, POONSs maintain greater continuity and insight, taking a longer-term perspective to patient and family care and adopting different attitudes concerning the quality of families' lives. In regional centres, these attitudes, it is felt, sometimes positively challenge those of other senior hospital staff who are driven by more curative quests: 'the consultant involved recognised the fact that the child was dying but still wanted tests and things to be
done.... [POONS 5] was so useful because she saw things from a slightly different angle.. I mean it worked fantastically and we stopped doing the blood tests’ (SHO3, Moorcroft Children’s). For several SHOs, POONSs’ insight is manifested in the closer relationships which some families develop with POONSs compared to other members of staff. This closeness is again, as with the PHCTs (see Chapter Eight), brought about through POONSs’ abilities to boundary hop between the hospital and the community. For the SHO at Westlands, families develop relationships with POONSs that are closer than those established with other members of staff because the CLIC nurse is: ‘the middle of a ring through which everything else evolves around’ (SHO2, Westlands District Hospital).

Summarising, this section discusses issues common to SHOs. It highlights a variety of relationships which SHOs develop with POONSs. It also describes how relationships developed with POONSs differ from or are similar to those cultivated with other nursing staff. Furthermore, it discusses how SHOs see the attitudes and working practices of POONSs differing from other staff they work with and illustrates the ways SHOs view relationships between families and POONSs.

**Sisters’ Narratives**

Sisters’ (n=6) have lengthy work experiences, not only on the units they are employed, but also working with POONSs. For most, relationships with POONSs extend beyond their current sisters’ positions, to times when they themselves worked as SNs. One however, predated the existence of POONS services by many years. Sisters have consequently ‘grown up’ alongside POONSs. How sisters picture the work of POONSs varies across the three case study sites, most particularly differing between the regional centres and Westlands. Issues common to all sisters in this study are discussed in this section of the chapter and participants are profiled in Table 9.1.

**The Evolution of POONS Services**

Major changes in the management of health care in general and of childhood malignancy in particular have occurred in recent decades (see Chapters Two & Four). Change is particularly apparent at regional centres where the pace exceeds that of
DGHs, who take their lead from specialist centres: ‘it’s very easy being in a backwater to get stuck in a rut cos we’re not up with all the current thinking’ (Sr2, Westlands District Hospital). Recent change in both ideology and management has meant that sisters at regional centres currently recognise that children and their families are better cared for locally wherever possible. This ideology is held to be partly responsible for bringing about either the naissance of POONS services or changes within existing services; sisters at both the Southern and the Northern had been party to such change. One commented:

"there’s a lot they had to do for Macmillan to get themselves sorted before they got themselves moving and then when they did get themselves moving there was only one person left"

(Sr5, Northern City Children’s)

Sisters³ at regional centres have observed positive transformations in patient care in recent times. Not least, POONSs are seen to influence the decreased amount of time children and their families spend in hospital. This is achieved through providing specialised nursing care and advice at home which would otherwise be provided in hospital, facilitating local communities to participate in care, or a combination of these factors. Such transformations have been observed from diagnosis through to terminal care. At the Southern for example, through recent expansion of the POONS service, all children currently gained support from POONSs, not just those who were terminally ill. Newly diagnosed children receiving treatment and their families are now well supported in the community by POONSs at each regional case study site. As part of this support, on one surgical ward at the Northern, families are currently psychologically prepared, by POONSs, well in advance of what is deemed to be disfiguring surgery: ‘now we notice that they come in and they’re so calm that we’re thinking that something’s wrong!’ (Sr1, Northern City Children’s).

³ ‘Sisters’ include all of those interviewed at regional centres. They worked either in OPD, on wards or on the BMT unit.
Terminally ill children and their families also currently receive continuity of care from POONSs, averting unnecessary visits to hospital. This point is exemplified by sisters at the Northern who, prior to the establishment of the POONS service, had visited families caring for dying children at home, in their own time. Such families often returned to the hospital when staff were unable to visit them at home or when, constrained by time, they were unable to provide the support which PHCTs demanded of them. It is also illustrated by the Southern, where, even though palliative care had been provided at home by POONSs for longer, it had greatly improved: ‘my earliest contact with them was that they were tending to do symptom control at home but not as extensive as it is now’ (Sr4, Southern Regional Hospital). In contrast, little change in the POONS service at Westlands has been observed over the years, maintaining a constancy in caring for all children with malignant disease: ‘through the whole time that I’ve known her she’s been CLIC nurse here’ (Sr2, Westlands District Hospital).

Change instead exists in the future as new ideals in community and advanced nursing practice are implemented. Talking of a new PCN service, the ward sister commented:

> they (children with cystic fibrosis) should get as much support as you know, the children with oncology... but they don’t, but hopefully they will. That will sort itself out hopefully to get a better service

(Sr2, Westlands District Hospital)

**Relationships with POONSs**

Maturation of POONS services has an impact on sisters’ relationships with POONSs; they are evolutionary, growing and changing with time. During the early years of POONSs at the Southern for example, there was little need for contact between sisters and POONSs - children who are terminally ill at home rarely require ward nursing time and are the domain of POONSs. Team expansion however, led to greater communication between POONSs and sisters - information about children receiving chemotherapy, who move between the hospital and the local community, is exchanged between them. Similarly, a recent change in the structure of the POONS team at the Northern had resulted in good, regular communication between POONSs and sisters. An early appointment to the POONS team had been unpopular with most senior members of the oncology unit; new appointments to the POONS team had recently
been made bringing about the good relationships currently enjoyed by sisters. Furthermore, the present stability of the POONS team enabled sisters to have more time to concentrate on ward/OPD-related issues as they were no longer occupied with 'phoning PHCTs about terminally ill children or contacting families between treatments. As the sister to the OPD said:

*families feel very vulnerable when they first go home. We tried to have a policy for a while where we'd ring them the day after discharge and that's OK if we were able to do it -*

(Sr6, Northern City Children's)

POONSs at regional centres offer a service to families which is complementary, supplementary but integral to the work provided by the sisters. They fill gaps between hospital and community-based services which were previously partially or wholly unmet. Here, POONSs backup in the community care provided by sisters and other hospital-based staff in the hospital. By contrast, the CLIC nurse at Westlands has little impact on the ward sister's work since each has defined, separate areas of work. However, the nursing care of children admitted to the ward for chemotherapy treatment is sometimes handed over to the sister or senior SN in charge of the ward when the POONS goes off duty, necessitating close communication. Whether backing up the care of the oncology unit or conducting entirely different work, distinctions between the work of POONSs and sisters ensure that individual professional identities exist. The sister at Westlands for example, viewed her own area of work to concern general paediatrics, whilst the POONS provided nursing care solely to children with malignant disease and their families. Sisters at regional centres viewed POONSs to have expertise in palliative care, symptomatic management, counselling and community nursing issues which they lacked; their own expertise lie in acute areas of care such as BMT and chemotherapy administration. These distinctions brought about a respect by sisters for the work which POONSs do. Different areas of expertise are epitomised by a sister who said:
theirs (expertise) is all community-based - pain and symptom control, but mine's very much into the intensive chemotherapy, bone marrow transplant after care. I see them as the experts in that and will draw them in to help us on those issues. I wouldn't begin to say I was an expert on pain and symptom control, I can for acute mucositis

(Sr3, Southern Regional Hospital)

Holding senior nursing positions brings about stress. Having independent identities means that the stresses endured by POONSs differ from sisters. The sister at Westlands for example, considered that nursing dying children is depressing and can be stressful. POONSs' work therefore carries more stresses than her own. Sisters at regional centres however, considered that the attitudes adopted by some PHCTs towards caring for dying children are difficult and stressful to work with: 'the recommendation was that they (the child) had a certain dose of narcotics...well the adult community nurse said, "no way can the child have this dose!"' (Sr5, Northern City). Furthermore, crossing the boundaries between the hospital and the community hinders the peer group support which sisters benefit from when enduring particularly stressful situations. In addition, sisters at the Northern felt that stresses experienced by POONSs are compounded by twenty four hour on-call provision. Being on call, they felt, obstructs POONSs' abilities to escape the clutches of demanding families. Comparing the demands of 24 hour on call with her own stresses, one concluded:

we would expect to get a night's sleep because we have night staff?

(Sr5, Northern City Children's)

Decision-Making Abilities and Responsibilities

At Westlands, consultants make decisions about children's care. However, the ward sister does rely on the POONS for instructions about nursing requirements of children with malignant disease, particularly those admitted to the ward, who are handed over to her at the end of the day. In contrast, at regional centres sisters share the ability to make 'medical' decisions about patients with POONSs. They do so through maintaining their own expertise and working closely with both POONSs and their medical colleagues. The abilities which lead them to make decisions about patient care also mean that teaching responsibilities are shared between regional POONSs and
sisters. Despite these shared responsibilities, POONSs possess greater abilities to make decisions compared to sisters because their jobs are more autonomous. The community-focused nature of the work also requires that POONSs undertake more teaching than sisters. The decision-making responsibilities of sisters and POONSs and the increased autonomy of POONSs is depicted by one sister who said:

[OPD Sister] and I make a lot of decisions, a lot of medical decisions...when you're a junior member of staff you don't do that...not as much as [POONS 1] sure, but then we have a lot of other worries

(Sr4, Southern Regional Hospital)

To recap, this section highlights issues common to ward and OPD sisters. It suggests that sisters have long, well-established relationships with POONSs which often predate either the establishment of POONS services or their own posts. For sisters at regional centres, this has meant that much change has been experienced and shared with POONSs, bringing about close working relationships. It also contends that sisters' roles are distinct from POONSs, creating clear professional identities between them. However, whilst POONSs at regional centres complement the work of ward and OPD sisters, the work of the CLIC nurse is predominantly independent of the sister at Westlands. The more specialised nature of the POONS at Westlands means that the ward sister relies on the POONS for instructions about how and when to nurse children with cancer and sees POONSs' work to be more stressful then her own. Sisters at regional centres however, it suggests, share responsibilities and stresses, albeit of different natures, with POONSs.

Consultants' Accounts
Hospital consultants (n=8) have similarly long histories to sisters of working with POONSs. A few more recently appointed consultants at regional centres for example, had worked with POONSs since they were registrars, either at the hospital in which they were currently employed or at an alternative UKCCSG centre. Most however, pre-dated the existence of POONSs and were involved in the naissance of POONS
services; some were responsible for procuring funds. Equally, one of the consultants at Westlands had known the POONS she worked with since her days as the ward sister, whilst the POONS’s lengthy work history had facilitated the passage of a second into her own more recent appointment. The consultants who participated in this study are summarised in Table 9.1.

Prior to working with the team of POONSs they currently worked with, consultants at regional centres had preconceived ideas about POONSs’ roles. These views however varied and concerned: operating like other CNSs within the hospital, advising hospital-based staff about disease-related or treatment-related symptoms experienced by in-patients: ‘I thought that the [POONS] team was simply there to control symptoms on an in-patient basis... like the pain control team that come round and are really good’ (Consultant 1, Moorcroft Children’s); providing comparable services to those offered by POONS teams at other UKCCSG centres: ‘when I came I assumed they would have much the same role as the people (POONS)s at Moorcroft’ (Consultant 6, Southern Regional Hospital); enhancing shared care between tertiary and secondary hospitals for families whose children receive chemotherapy: ‘a model which was geographical with a specific link to support each share care centre’ (Consultant 5, Northern City Children’s) or, and in contrast, focusing solely on improving care of families whose children were terminally ill at home.

In general, regional consultants’ impressions of POONS rôles had altered with time - POONSs were considerably more successful than initially anticipated and their functions more diverse. The successes of services and consultants’ altered perceptions were commonly attributed to the hard work and efforts of POONSs and to consultants own misguided preconceived ideas. Changes within both POONS services and the management of paediatric oncology were also held responsible for their altered views. Consultants’ changed perceptions of POONS work are epitomised by one who said:

4 For simplicity, the senior medical staff who participated in this study from Westlands have been referred to as ‘consultants’. One of the senior medical staff was in fact an Associate Specialist.
I think what we weren't clear about was exactly how important they would be in the different areas...what's emerged I think is that they are seen to work more with the primary health care team

(Consultant 5, Northern City Children's)

By contrast, little at Westlands had changed. CLIC had been instrumental in the naissance of the POONS service; neither consultant had been involved in ground work to establish the post nor did they possess preconceived ideas about the function of POONSs other than to: 'improve the services to the children with cancer' (Consultant 2, Westlands District Hospital). Two changes which had occurred in recent times however, included firstly the appointment of a full time consultant with a specific interest in paediatric oncology. Prior to her appointment, the CLIC nurse had taken medical advice from a consultant in a neighbouring DGH, some 20-30 miles away. Secondly, due to NHS reorganisation, the POONS's catchment area had been decreased and the POONS had accordingly reduced her working hours. Her work however, and consultants' views remained unchanged.

The Aims of POONS Services

All consultants currently considered that POONSs provide support to families across the disease spectrum, from diagnosis to outcome, be it death and bereavement or cure. Prior to POONS services at regional centres this support was partially or wholly lacking. POONSs therefore filled previously vacant gaps in the overall services provided by the oncology unit: '[POONS 1] was recruited in order to fill a big gap' (Consultant 7, Southern Regional). In contrast, the POONS service at Westlands relieved consultants of unwanted tasks and generally 'nannies' families: 'someone to keep those awful charts up to date (and)... chasing up the ones who are coming in to be treated, helping them through their treatment...just improving things' (Consultant 2, Westlands District Hospital). Furthermore, the CLIC nursing service inadvertently created a two tier structure whereby children with malignant disease and their families received comprehensive support whilst children with other chronic, life-threatening or life-limiting diseases received minimal care in the community. Nevertheless, emphasis, it was felt, is placed by POONSs at each case study site, upon providing care and support to families during terminal illness. Links between
local communities and regional centres are also provided, albeit differently between regional POONSs and the service at Westlands (see the accounts of SNs).

Contact With POONSs
Contact between hospital consultants and POONSs varies. In the main, consultants have frequent and regular contact with POONSs. However, a small number have infrequent contact. Communication between POONSs and consultants may be informal and, at regional centres, formal. Consultants at Westlands for example described regular informal contact between themselves and the CLIC nurse, frequently passing each other on the ward, bumping into one another over coffee or informally discussing patients when consultants make decisions about care. Similarly, consultants at both the Northern and the Southern had frequent informal discussions with POONSs. This informal contact is illustrated by one consultant who said:

if there's anybody in particular they want me to be involved in they would just come and get me

(Consultant 7, Southern Regional Hospital)

In addition, regular formal contact occurs between most consultants at regional centres and POONSs. This arises from attending multidisciplinary ward rounds when POONSs frequently relay and exchange information about families they have visited at home and/or meetings specifically with POONSs to discuss issues extrinsic to the wider domain. Again, Consultant 7 at the Southern Regional best illustrated this point by saying: ‘there are sometimes things that aren’t for general consumption, there are problems within the family which shouldn’t just get broadcast to 20 people because 20 people don’t need to know sometimes’. In contrast, at Moorcroft Children’s there is infrequent formal or informal contact between POONSs and consultants. Here, consultants recognise the greater skills of POONSs, in palliative care and leave them to make decisions regarding the management of terminally ill children.
POONSs' Professional Backgrounds
Consultants possess great insight into the professional backgrounds of POONSs. For consultants at the Northern in particular, educational and professional backgrounds of POONSs had been a particular issue. Firstly, their ideals and those of their senior nursing colleagues conflicted with criteria set down by CRMF. Secondly, early experiences of working with a particularly unpopular POONS who had complied with CRMF’s measures, evoked much discussion amongst senior nursing and medical staff at the hospital. At the outset, CRMF had required POONSs to have community nursing backgrounds whilst senior staff at the Northern leant towards a comprehensive background in paediatric oncology nursing. Against the hospital staffs’ wishes, POONSs initially appointed at the Northern were all community-trained. Despite this, consultants at each regional centre currently considered that POONSs should have professional backgrounds in community nursing as well as paediatric oncology. This is represented by a consultant at the Northern talking about the CRMF criteria. He commented: ‘it’s interesting talking to that person who subsequently got the (POONS) job when the team was reshuffled, because of course she now acknowledges that some perspective on community care is actually quite important’ (Consultant 5, Northern City Children’s). In comparison, consultants at Westlands valued the extensive general paediatric nursing experience of ‘their’ POONSs.

Comparing POONSs with Sisters
Ward sisters and POONSs are highly regarded by the consultants they work with and, for the most part, sisters are considered to be equally as experienced as POONSs. However, their expertise differs. The acute, high-tech nature of ward work at regional centres ensures that consultants share with ward sisters an overlapping knowledge base from which solutions to problems are jointly worked through. Some regional consultants however, felt that POONSs possess a greater depth of theoretical knowledge than sisters, on which they have to rely to make their own judgements. Whether ‘just different’ or ‘more expert’, subtle differences exist between the relationships consultants develop with ward sisters and POONSs. One consultant said:
I think the relationship I have with the senior nurses on the ward is almost but not quite the same... I'm probably much more prepared to interfere with what goes on on the ward because it's so much more immediate and because it's often more acute... the most senior nurses are as skilled (as POONSs) but they're working in a different way

(Consultant 5, Northern City Children's)

Both the ward sister and the POONS at Westlands are involved in discussions with consultants about the treatment decisions consultants make. A major difference for consultants however, between the ward sister and the POONS, lay in the POONSs' greater knowledge and insight into families' dynamics: 'she certainly has... a very, very in-depth knowledge of families... and probably a ward sister would never quite have that' (Consultant 3, Westlands District Hospital).

The teaching commitments of POONSs and sisters were also compared by consultants at regional centres. Each shared a belief that senior nursing staff (both sisters and POONSs) are well suited to teaching junior doctors as well as nursing staff. Consultants at the Southern for example considered sisters and POONSs equally share responsibilities to teach junior staff, albeit maintaining their own specialist areas. Those at both the Northern and Moorcroft however, felt that POONSs' abilities to teach junior staff exceeded those of sisters because they had more confident personalities, greater experience speaking publicly to groups and at conferences and in some situations, as discussed above, greater expertise. Conversely, although SHOs sometimes defer to the CLIC nurse, junior doctors at Westlands are generally taught by consultants. In contrast to the expertise and teaching abilities of POONSs at regional centres, the POONS at Westlands herself, consultants believed, needs constantly updating by staff at Westcliff in order to maintain her expertise.

In summary, this section of the chapter addresses issues common to consultants. Like sisters, it suggests that consultants have lengthy histories of working with POONSs; for some this concerns the inception of the POONS service they currently work with and procuring funds. These lengthy histories ensure that many consultants had preconceived ideas about POONS services at the outset which have largely changed with time. It describes how consultants currently perceive the work of POONSs and
the differing relationships they have developed with them. It also tells of the different perceptions between sisters’ and POONSs’ roles and highlights the professional backgrounds which consultants consider POONSs require to undertake their work.

Conclusion
This chapter examines qualitative data from the second stage of the research to descriptively portray hospital-based health care professionals’ experiences of working with POONSs. It suggests that staff in hospitals encounter POONSs as part of their day-to-day working lives but that their experiences of working with POONSs differ according to their level of seniority and locality. In the main, senior nursing and medical staff have greater contact with POONSs than juniors. However, there are some situations and locations in which junior staff also have frequent communication with POONSs. For senior staff at regional centres, relationships with POONSs were evolutionary, developing and growing with time. This process however, was less apparent at Westlands where change occurs at a slower pace. Junior staff became familiar with the work of POONSs in a variety of ways. Some had had formalised induction programmes from which an understanding about POONSs’ roles had arisen and close relationships developed. Others, in contrast, had little understanding about POONSs’ roles and felt they were unconnected to the main ward activities. Nevertheless, POONSs’ roles were viewed by all to differ significantly from other senior nursing roles. The narratives of all hospital-based health care professionals recounted in this chapter, are built upon in subsequent chapters. Firstly in Chapter Ten, along with data from the POONS survey, the experiences of those working with POONSs are drawn upon to discuss ‘specialist’ knowledge. Later in Chapter Twelve, also incorporating data from the POONS survey, a partnership typology between POONSs and hospital-based health professionals is developed.
Chapter Ten - ‘All POONSs are Specialists, Some POONSs are More Specialist than Others’

Introduction
Being a ‘specialist’ and being ‘knowledgable’, both through dictionary definition (Longman 1986) and the accounts of health care professionals participating in this study, share similar characteristics. These are derived from experience, formal training or both. Therefore throughout this chapter ‘specialist’ and ‘knowledgable’ are used interchangeably. In adopting and adapting George Orwell’s (1945) slogan from Animal Farm: ‘All POONSs are specialists, some POONSs are more specialist than others’, this chapter examines ‘specialist’ knowledge. In so doing it suggests that, whilst all POONSs are perceived to possess ‘specialist’ knowledge and be ‘specialists’ relative to their colleagues, the degree to which these are achieved is influenced by the strategies adopted by the funding organisations associated with their work.

Drawing on data from both stages of the research, ‘specialist’ knowledge is constructed from two perspectives. Firstly, the chapter draws on quantitative data from the POONS survey to suggest that, on the one hand ‘specialist’ knowledge is professionally constructed through the demands the profession places upon itself to achieve a professional status. These demands are examined through both the professional training and past experiences of POONSs. Both training and experience are interlinked and integral to becoming a ‘specialist’ and developing ‘specialist’ knowledge. Both in turn, the data suggest, vary according to the ‘Funder’ models with which POONSs are associated.

On the other hand, this chapter uses the case study data to contend that whilst ‘specialist’ knowledge varies according to the strategies adopted by the funding organisations associated with POONSs, in the main, health care professionals disregard professional demands and confer ‘specialist’ status on POONSs according to their own personal agendas and experiences. Here, all POONSs are regarded as specialists in their field, irrespective of the degrees of ‘specialist’ knowledge they attain through formal training and professional experience. Instead, ‘specialist’ status
is dependent upon the level of experience individual health care professionals have themselves gained in childhood malignancy, the hospital location of the POONS/s with whom they work and the professional backgrounds of particular POONS/s. Differences in conferring ‘specialist’ status to POONSs predominantly exist between health care professionals working with the CLIC nurse at Westlands and those working with regionally-based POONSs. ‘Specialist’ knowledge is drawn upon later in the thesis to suggest that the way in which the concept is perceived, particularly by hospital-based health care professionals, impacts on the relationships they develop with POONSs. This chapter also contends that health care professionals construct ‘specialists’ around personalities. In so doing, it suggests that not only must POONSs have the correct professional attributes to fulfil their perceptions of a ‘specialist’, but they must also have the ‘right’ personality. The training, experiences and personalities of POONSs and the experiences of those they work with are the focus of this chapter.

**Professionally Constructing ‘Specialist’ Knowledge**

Embodied in the ‘professional project’ of nursing is the acquisition of a specialist body of knowledge (e.g. see Hugman 1991, Macdonald 1995, Beattie 1995). It has been argued earlier in this thesis that the process of acquiring specialist knowledge is embedded in both training and experience (for example see Benner 1984, Hamric 1992, Lipman & Deatrick 1994, MacLeod 1996). Furthermore, to achieve the status of CNS, a high degree of specialist knowledge, grounded particularly in training, is desirable (Castledine 1982, 1983, RCN 1988, Hamric 1992, Lipman & Deatrick 1994). Examining quantitative data from the POONS survey, this section of the chapter discusses the two components which constitute ‘specialist’ knowledge: professional training and experience. It will argue that training and experience are intertwined so that both influence the degrees to which POONSs acquire ‘specialist’ knowledge. In examining the qualifications attained by POONSs, the experiences they perceive to be important to their work and the levels of seniority achieved prior to their POONS appointments, it is contended that the mixed funding sources of POONSs influence the degrees to which ‘specialist’ knowledge is achieved. These factors contribute to the notion that: ‘All POONSs are specialists, some POONSs are more specialist than others’.
The development of 'new' nursing specialties, such as POONSs, means that nursing 'entrepreneurs' have no one particular specialist training or area of practice on which to draw. Furthermore, highly specialised areas of nursing work, such as that undertaken by POONSs, frequently encompass several specialist fields. The foundations of POONS services predominantly embrace and have built on, sick children's nursing, cancer nursing\(^1\) and community nursing. However the extent to which 'specialist' knowledge in each of these fields had been acquired by POONSs at the time of this study, whether through training, experience or both, is limited, with few POONSs having prior knowledge of all three areas (Tables 10.1 & 10.2).

The work of POONSs further draws on palliative care and counselling. In addition, POONS roles, like other CNSs (e.g. Castledine 1982, 1983, Storr 1988, Miller 1995), may comprise research and teaching elements. Consequently, experience and specialist training undertaken by POONSs in this study is wide ranging (Tables 10.1 & 10.2). Taking professional qualifications and experience independently, this section suggests that the strategies adopted by the two main charities funding POONS posts impact on both their training and experience. In so doing, it contends that POONSs identified with the CLIC 'Funder' model attain a lower level of formally measured 'specialist' knowledge, whilst POONSs associated with the Macmillan model comply with the charities requirements and fit expectations demanded of CNS posts more closely. The first component of 'specialist' knowledge to be addressed is qualifications.

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\(^1\) Early POONSs relied on the ENB 237 course in adult cancer nursing. Later appointees have undertaken the ENB 240 Paediatric Oncology course. Throughout this thesis, distinctions between the two qualifications are not made.
Table 10.1 Professional qualifications attained by POONSs comparing ‘Funder’ models

<table>
<thead>
<tr>
<th>QUALIFICATIONS ATTAINED</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan (N=5)</td>
<td>CLIC (N=10)</td>
</tr>
<tr>
<td>Nursing degree</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Nursing diploma</td>
<td>1 (20%)</td>
<td>-</td>
</tr>
<tr>
<td>RGN</td>
<td>5 (100%)</td>
<td>8 (80%)</td>
</tr>
<tr>
<td>RSCN</td>
<td>5 (100%)</td>
<td>9 (90%)</td>
</tr>
<tr>
<td>EN</td>
<td>-</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Community (HV/DN)</td>
<td>3 (60%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Teaching (ENB 998/C&amp;G 730)</td>
<td>3 (60%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Care of the Dying (ENB 931 or equivalent)</td>
<td>3 (60%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Oncology Nursing Certificate</td>
<td>2 (40%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Counselling Certificate</td>
<td>2 (40%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (60%)</td>
<td>3 (30%)</td>
</tr>
</tbody>
</table>

n.b. Total exceeds 100% since more than one response given by individuals
Table 10.2  Previous relevant experiences comparing 'Funder' Models

| PREVIOUS RELEVANT EXPERIENCE | FUNDER MODEL | | | TOTAL |
|-----------------------------|--------------|------------|------------|
|                             | Macmillan (N=5) | CLIC (N=10) | 'Mixed Funders' (N=28) | |
| Professional:               |              |            |            | |
| Paediatric Oncology         | 4 (80%)      | 2 (20%)    | 17 (61%)   | 23 (54%) |
| Other paediatric nursing    | 2 (40%)      | 7 (70%)    | 17 (61%)   | 26 (60%) |
| Community nursing           | 3 (60%)      | 3 (30%)    | 7 (25%)    | 13 (30%) |
| Other nursing               | 1 (10%)      | 3 (30%)    | 5 (18%)    | 9 (21%)  |
| Training                    | 2 (20%)      | 3 (30%)    | 5 (18%)    | 10 (23%) |
| Personal:                   |              |            |            | |
| Serious Illness             | -            | 2 (20%)    | 4 (14%)    | 6 (14%)  |
| Personal Bereavement        | 3 (60%)      | 3 (30%)    | 4 (14%)    | 11 (25%) |
| Being a parent              | 1 (20%)      | 3 (30%)    | 5 (18%)    | 7 (30%)  |
| Other                       | 1 (20%)      | 2 (20%)    | 10 (36%)   | 13 (30%) |

N.B. Totals exceed 100% since more than 1 response given by individuals
Qualifications

As suggested above, there is no statutory training requirement to become a POONS. However, nurses attaining specialist status are expected to have undertaken training beyond registration (Castledine 1982, 1983, RCN 1988, Hamric 1992, Lipman & Deatrick 1994, UKCC 1996). This section examines the professional qualifications attained by POONSs to suggest that the strategies adopted by the two main charities associated with funding their posts, influence the degree to which both registration and post registration training is achieved. It suggests that the strategies adopted by CLIC result in CLIC-funded POONSs attaining the least number of professional qualifications. In contrast, CRMF’s strategies result in MPNs attaining a wide range of qualifications which are pertinent to their work (Table 10.1).

Those POONSs identified with the CLIC model generally attained fewer basic and post basic qualifications than those affiliated with the other two ‘Funder’ models (Table 10.1). Fundamental to the rights of sick children to be nursed by trained sick childrens’ nurses, either in hospital or at home (DoH 1996a, 1996b), nine out of ten CLIC nurses had accomplished the RSCN qualification. One POONS had attained neither RSCN or RGN and practised as an EN. Reflecting the nature of the specialty and the rôles of CNSs’, very few CLIC nurses were trained in cancer nursing (n=2), had studied for the ENB Care of the Dying Certificate (n=1) or possessed teaching qualifications (n=1).

In contrast and in common with CRMFs’ recommendations (CRMF 1992), a greater proportion of MPNs had accomplished the ENB Certificate in Care of the Dying (n=3), community nursing qualifications (n=3) and teaching certificates (n=3) than those funded by other organisations (Table 10.1). The attainment of a community qualification in addition to supporting CRMFs’ recommendations, also corresponds to recent thinking relating to professional training expected of the specialist nurse whose work extends into the community (e.g. Wade & Moyer 1989, NHSME 1993) and to creating harmonious relationships between community nurses and CNSs (Williams 1993). Others (e.g. Kitson et al. 1987) have also suggested that RSCN training alone ill equips hospital-based nurses working in the community. It might
therefore be argued that the community nursing qualification recommended and attained by most MPNs (3 out of 5), best fits recent professional recommendations.

A feature of the professional training undertaken by POONSs affiliated with the ‘Mixed Funders’ model concerns cancer nurse training. More POONSs in this group had achieved ENB certificates in cancer nursing than others (12 out of 28). It is possible that the professionally-led approaches of the funding organisations associated with this group of POONSs, coupled with the recognition by hospital-based health care professionals at regional centres that primary and secondary services lack the knowledge required to care for children with malignant disease, led to this characteristic. As will be shown later in this chapter, health care professionals at all levels working in regional centres, expect that a basic requirement of attaining senior nursing status is to have undertaken cancer nurse training. With this in mind, it is probable that during the early days of POONS services, selection panels of senior hospital-based health care professionals gave preference to those with oncology training, believing this to be the primary post-basic professional qualification required.

In summary, the philosophies of the funding organisations associated with POONSs are linked to the professional qualifications attained by POONSs. The strategies of CRMF have determined that MPNs have a wide range of post registration ‘specialist’ professional qualifications. In a similar vein, the beliefs of health care professionals working at regional centres involved in appointing POONSs affiliated to the ‘Mixed Funders’ model, have ensured that this group of POONSs are more commonly trained in cancer nursing. However, the strategies of CLIC to provide locally-based services, thereby fulfilling the needs of generic paediatric staff, have resulted in minimal ‘specialist’ training being undertaken by POONSs associated with the CLIC model. Not only this, but not all have attained basic registration.
Experiences

It has been argued that 'specialist' knowledge is gained through both experience and professional training. The previous section showed that mixed funding sources of POONSs have brought about discrepancies in the 'specialist' qualifications accomplished by POONSs. This section suggests that diversity in the previous experiences of POONSs also exists, which is similarly influenced by the strategies of the charities funding their work.

'Experience' is discussed through examining past experiences which POONSs value and which they say benefit their work and the previous positions attained by POONSs. In this study past experiences fall into two categories: professional and personal. It has earlier been contended that professional training is entwined with professional experiences and that the degrees to which both frame 'specialist' knowledge are influenced by charities’ strategies. In this case, POONSs with limited 'specialist' training such as those affiliated with the CLIC model, value their more general nursing experiences, either in paediatric settings or in other fields (Table 10.2). In this situation, basic nurse training is also a valued experience to undertake POONS work and this is similarly observed in POONSs identified with the CLIC model (Table 10.2). Conversely, POONSs with more specialised training draw more heavily on their past experiences in specialist fields. In this instance, reflecting the ideologies of CRMF, MPNs drew on their experiences working in the community and in paediatric oncology.

In the main, organisations funding ‘Mixed Funders’ POONSs work closely with the professionals at the hospitals to which they are linked (Chapter Three). This close relationship has accounted for a preponderance of ‘Mixed Funders’ POONSs being appointed internally (see Chapter Six). Furthermore, a greater number of ‘Mixed Funders’ POONSs had been promoted from SNs directly into POONS positions (Table 10.3). Although many POONSs in this group had gained a wealth of experience in paediatric oncology (exceeding that of MPNs), less than two thirds of POONSs associated with the ‘Mixed Funders’ model cited cancer nursing as relevant past professional experience to undertake the work of POONSs (Table 10.2). The
reason for this is unclear, but may be a result of both the internal nature of many appointments and the more junior status previously achieved by this group of POONSs. In addition, given most health care professionals at regional centres expect POONSs to have gained professional backgrounds in paediatric oncology, citing previous exposure to paediatric oncology nursing may have seemed obvious, with POONSs in this group drawing on the experiences gained from other, more remote jobs.

Table 10.3 Previous position of each POONS, comparing ‘Funder’ models

<table>
<thead>
<tr>
<th>Previous position</th>
<th>FUNDER MODEL</th>
<th>TOTAL (N=43)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan (N=5)</td>
<td>CLIC (N=10)</td>
</tr>
<tr>
<td>SN</td>
<td>1 (20%)</td>
<td>-</td>
</tr>
<tr>
<td>Sr</td>
<td>1 (20%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Other¹</td>
<td>3 (60%)</td>
<td>4 (40%)</td>
</tr>
</tbody>
</table>

¹ Including community nursing positions
* See List of Abbreviations

In the absence of qualifications and ‘specialist’ work experience, value is placed on personal experiences such as being a parent or having personally encountered serious illness. CLIC nurses drew more heavily on personal life experiences than those working at regional hospitals (Table 10.2). The exception to this were MPNs who suggested that personal bereavement readily enabled them to empathise with the families in their care. It is not possible to know whether MPNs had experienced personal bereavement to a greater extent than others. However it is possible that the emphasis placed on terminal care and bereavement work by CRMF is responsible for this feature (see Chapter Six).

In conclusion, this section of the chapter has examined the professional qualifications and past experiences, both professional and personal, of POONSs. In so doing it has suggested that the strategies adopted by the organisations associated with funding the work of POONSs are linked with differences both in the qualifications and previous
experiences of POONSs. It has suggested that POONSs associated with the Macmillan model, in accordance with CRMFs' philosophies, acquired a wide range of qualifications pertinent to their work. With the exception of personal bereavement, they also drew heavily on professional backgrounds when discussing previous experience. The 'Mixed Funders' model contained higher proportions of POONSs trained in oncology, corresponding to the ideals of health care professionals working in paediatric oncology units who direct the funding organisations associated with this model. Similarly, the strategies of CLIC have been responsible for CLIC nurses having the least number of professional qualifications and, in the absence of specialist qualifications, placing greater emphasis on personal life experiences. Thus it is argued that CLIC nurses do not acquire the same degrees of 'specialist' knowledge as POONS associated with either of the other two 'Funder' models. From a professionally-driven agenda, CLIC nurses do not therefore acquire the high degree of 'specialist' knowledge, obtained through professional training, which is demanded of CNS positions.

Conferring 'Specialist' Status on POONSs

The first part of this chapter has discussed 'specialist' knowledge from a professionally-driven agenda. In so doing, it has suggested that different levels of 'specialist' knowledge are attained by different groups of POONSs, through both their professional training and professional experiences and, where these are lacking POONSs draw more heavily on personal life experiences. These different levels of knowledge, it is argued, are influenced by the mixed funding sources of POONSs.

In contrast, this section of the chapter suggests that health care professionals, ignoring professional agendas, more usually confer 'specialist' status on POONSs according to their own experiences and agendas. Perceptions of 'specialist' knowledge are contingent upon the level of experience health care professionals have themselves gained in childhood malignancy, the hospital location of the POONS/s with whom they work and the professional background of the POONS/s they work with. Perceptions of 'specialist' and therefore 'specialist' knowledge are subjective: anyone who has more experience or is more specialised than another individual may be
deemed a 'specialist'. Consequently, being a 'specialist' is perceived differently by PHCTs, junior and senior hospital staff, and by staff at regional centres and DGHs, holding different meanings for each. This has resulted in 'specialist' knowledge being conferred to POONSs from two types of personal agenda. At one level, health care professionals with limited knowledge vis-à-vis aspects of paediatric oncology, and junior nurses embarking on 'specialist' careers, confer 'specialist' knowledge to POONSs through needs-driven agendas. Here, health care professionals look to POONSs to fill knowledge gaps. In this situation all POONSs, regardless of training and past experience, are viewed as 'specialists'. At a second level, health care professionals with greater understanding of paediatric oncology and the work and backgrounds of POONSs, bestow 'specialist' knowledge on POONSs through peer-driven agendas. Here, 'specialist' knowledge of POONSs is distinguished from that of other 'specialists'. It also concerns the professional well-being of POONSs. In this agenda: 'All POONSs are specialists, some POONSs are more specialist than others'.

When 'specialist' status is conferred upon POONSs the areas of knowledge considered by other health care professionals include formal qualifications, hands-on technical skills, previous 'specialist' work experience, in-depth 'medical' knowledge and insight into families’ dynamics (Figure 10.1). Personal life experiences, important to POONSs themselves in the absence of pertinent professional qualifications and experiences, contribute towards 'specialist' status only when considering POONSs’ personalities - they do not contribute towards 'specialist' knowledge per se. Different emphasis is placed on each conferred component of specialist knowledge, depending on the agendas of individual health care professionals working with POONSs. The relative contribution each of these makes towards constructing a 'specialist', primarily depends upon the regional or district location of POONSs (Figure 10.1). The factors which constitute both needs-driven and peer-driven agendas and the emphasis given to each component of 'specialist' knowledge are the focus of this section of the chapter.
Figure 10.1 Components of 'specialist' knowledge conferred on POONSs by other health care professionals

- **FORMAL QUALIFICATIONS**
  - Mainly Regional

- **HANDS-ON TECHNICAL SKILLS**
  - Mainly District

- **PREVIOUS ‘SPECIALIST’ WORK EXPERIENCE**
  - District and Regional

- **IN-DEPTH ‘MEDICAL’ KNOWLEDGE**
  - Only Regional

- **INSIGHT INTO FAMILIES’ DYNAMICS**
  - Only District
**Needs-Driven Agendas**

Some health care professionals who work with POONSs have professional needs either concerning caring for children with malignant disease or helping to pursue their own careers. This has led to personal, needs-driven agendas which contribute to health care professionals conferring 'specialist' knowledge on POONSs. Four examples of needs-driven agendas are discussed in this section of the chapter.

(1) A Knowledge Gap:
The experiences of PHCTs working with children with malignancy in particular, and sick children in general, differ and have earlier been described in Chapter Eight. Most GPs in this study had some past experience of childhood malignancy, either as paediatric SHOs, as paediatric registrars, as GPs or personally. Many HVs had encountered chronically sick children, the deaths of young adults with small children or bereaved parents. District nurses however, had extremely limited professional experience with children although they frequently encounter adults with cancer, terminally ill patients and bereaved relatives. Whatever their prior experiences of paediatric oncology, all are limited and are best represented by one DN who said:

> I've worked as a community nurse, I'm going into my twenty third year and this is only the second experience of nursing a terminally ill child at home

(DN5, Northern City area)

and by a GP who commented:

> I've never actually been in charge as it were, had responsibility solely, looking after a child with cancer, of being the main person in charge before. There's always been two, you know, other housemen or whatever, you know, the odd decisions you make are about, you know, 'Where do I put the drip?'

(GP10, Southern Regional area)

The personal, needs-driven agendas of PHCTs relate to these limited experiences - PHCTs need to understand how to care for sick children and their families before comprehending the more 'specialist' problems associated with paediatric oncology. In this scenario emphasis is placed on two of the components of conferred 'specialist'
knowledge: hands-on technical skills and ‘specialist’ work experience (Figure 9.1). How ‘specialist’ work experience is defined however not only depends on the past experiences of individual PHC professionals but also on the base of the POONS with whom they work. At one level, all POONSs achieve ‘specialist’ status since all have ‘specialist’ paediatric experience relative to PHC professionals’ needs. As one DN suggested: ‘(POONSs are) used to actually dealing with children’ (DN9, Southern Regional area). Hence nursing sick children, irrespective of the disease: ‘needs somebody who’s got experience of looking after children’ (DN2, Northern City area). However, at a second level work experience takes on a more ‘specialist’ perspective, suggesting that regional POONSs are more ‘specialist’ than those at DGHs. Whilst a basic cognizance of paediatrics is paramount to all PHCTs, reflecting the work location of regional POONSs, many PHC professionals working with regional POONSs consider ‘specialist’ work practice is specific to paediatric oncology. As one DN involved in the care of a newly diagnosed child commented: ‘she’s a specialist and I can’t possibly keep up with the (cytotoxic) drugs, you know, the current ones’ (DN15, Southern Regional area). In addition a GP talked about monitoring side effects of chemotherapy as: ‘something they’re seeing... everyday’ (GP19, Southern Region area).

Hence, all POONSs are ‘specialists’ since all possess greater paediatric knowledge relative to that of PHCTs. However, the ‘specialist’ knowledge conferred on POONSs by PHCTs, drawn from both hands-on technical skills and ‘specialist’ work practice, differs according to POONSs’ work locations. For PHCTs working with the POONS at Westlands, ‘specialist’ work experience is derived from POONSs’ experiences of general paediatrics. For those working with regional POONSs, it is derived from POONSs’ experiences of paediatric oncology.
(2) Resolving Anxieties:
A second example in which ‘specialist’ knowledge is conferred on POONSs by the health care professionals they work with, concerns resolving anxieties. District nurses, unused to nursing chronically sick children, experience a great deal of anxiety when faced with caring for a child with malignant disease. In this situation, anxieties may be resolved through the availability of ‘specialists’ with hands-on technical skills and previous work experience (Figure 10.1).

For junior SNs on a general paediatric ward, unused to nursing children with malignant disease but familiar with nursing sick children, anxiety also arises when caring for children with cancer or leukaemia and their families. ‘Specialist’ status, arising from SNs’ anxieties, similarly draws on ‘specialist’ work experience and hands-on technical skills. It may also draw on formal training. ‘Specialist’ knowledge derived from the needs of SNs to resolve their anxieties is epitomised thus:

I wouldn’t be able to cope with the bereavement side of things - I just feel very inadequate and I’d need a lot of training in that direction I think, with parents, with knowing what to say and then saying it
(SN8, Westlands District Hospital)

In conclusion, ‘specialist’ status is granted to POONSs through the needs-driven agendas of both DNs and SNs at DGHs, to resolve their anxieties. However, the stresses endured by these two groups of nurses both inexperienced in paediatric oncology, arise from different baseline perspectives. Whilst DNs and SNs at DGHs don ‘specialist’ status to POONSs through ‘specialist’ work experience and hands-on nursing skills, their definitions differ. For DNs, these skills pertain to paediatric nursing, whilst the hands-on skills and work experiences demanded by junior SNs at Westlands are specific to the needs of children with malignant disease.
Pursuing 'Specialist' Nursing Careers:

A third example of a needs-driven agenda in which 'specialist' status is accorded to POONSs concerns SNs pursuing careers - becoming a POONS is one option which is open to them. Contemplating future career pathways affects all junior SNs similarly, regardless of the environment in which they work; work experience and further formal qualifications assist SNs along the ladder of seniority and to attaining 'specialist' status. 'Specialist' status is conferred upon POONSs according to deficits in SNs' own knowledge which they would have to rectify before undertaking the work of a POONS (thereby becoming a 'specialist'), should they so desire. It is this need of SNs to rectify shortfalls in their own knowledge before attaining 'specialist' status, which contributes to a needs-driven agenda. However, 'specialist' knowledge is constructed differently according to the environments in which SNs work, the formal training and experiences of the POONS/s they work with and, for those at regional centres, current professional agendas. Furthermore, formal qualifications demanded by SNs to achieve the 'specialist' status of POONSs differ between regional centres and Westlands. Reflecting the past experiences of the CLIC nurse they worked with, SNs at Westlands overlooked professional agendas which desire that formal post-registration training be undertaken to attain 'specialist' status. Instead, they generally beheld 'specialists' as having extensive work experience and hands-on technical skills. In contrast, in addition to 'specialist' work experience, SNs at regional centres mindful of the professional demands nursing places upon itself to achieve 'specialist' status, drew more heavily on formal post basic qualifications.

Junior SNs at Westlands, untrained, training or newly qualified to care for sick children considered that 'specialist knowledge' is gained through extensive work experience following the attainment of the RSCN/RN(Child) qualification. It comprises 'specialist' hands-on nursing tasks (Figure 10.1) such as handling CVADs and administering intravenous drugs. These tasks are more routinely undertaken by SNs at regional centres. It may, for a few, comprise formal training attained through an ENB Certificate in cancer nursing. One SN commented:
you've got to have an overall paediatric knowledge....... learning and knowing about oncology problems, of treatments, of -

(SN7 Westlands District Hospital)

Reflecting both recommendations that nurses whose work extends into the community be trained in community nursing (Kitson et al. 1987, Wade & Moyer 1989, NHSME 1993, Williams 1993) and the backgrounds of the POONSs they worked with, SNs at regional centres envisaged that 'specialist' knowledge of POONSs comprised both formal community nurse training and 'specialist' experience in this field. Taking the premise that formal training and lengthy experience in both paediatrics and oncology is accomplished by all senior nurses working within the field of paediatric oncology, it is community nursing experience and formal training in this area of work which stand POONSs apart from other senior nursing staff. It is this field of work which regional SNs consider they need to undertake before achieving the 'specialist' status acquired by POONSs:

you have to have a community qualification to be in the community, I mean that's a criterion to be a community nurse, you can't otherwise do it

(SN11, Southern Regional Hospital)

(4) Knowing Families:
Community and hospital-based health care professionals acknowledged that POONSs develop especially close relationships with families (see Chapters Eight & Nine). This, it was deduced, arises because of POONSs' abilities to boundary hop between the hospital and the community. However, unique to the consultants at Westlands, the in-depth knowledge of families' dynamics, brought about through 'befriending' (Bignold et al.1995b) families, is seen as a skill of POONSs to be drawn upon (Figure 10.1). This gives rise to a fourth needs-driven agenda in which consultants depend upon this knowledge to assist them in making treatment-related decisions about patients. The reasons consultants at Westlands depend on this knowledge is

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2 Although less than a third of all POONSs had attained a community nursing qualification (Table 10.1), most regional staff interviewed during the case studies worked with community-trained POONSs.
unclear but may lie in consultants frequent provision of hands-on care to children, both in hospital and at home. In this situation, consultants are reliant on POONSs to teach them specialist technical ‘nursing’ skills such as accessing CVADs. To undertake such tasks requires ‘befriending’ the child with malignant disease and his/her family in order to gain their trust. Consequently, in this needs-driven agenda, consultants not only confer ‘specialist’ knowledge on POONSs through POONSs’ relationships with families, they also draw upon their ‘specialist’ hands-on skills.

In summary, needs-driven agendas are derived from four perspectives: knowledge gaps of PHCTs, anxieties experienced by some groups of nurses, career pathways of SNs and POONSs’ knowledge of families. Needs-driven agendas which drive health care professionals to confer ‘specialist’ status on POONSs are not only influenced by individuals’ experiences and agendas. They predominantly differ according to the hospital location and the background of the POONS/s they work with. These differences endorse the discrepancies in the professional qualifications and experiences between regional and district-based POONSs associated with the three ‘Funder’ models (Tables 10.1 & 10.2), concurring with the notion that: ‘All POONSs are specialists, some POONSs are more specialist than others’.

Peer-Driven Agendas
A second type of personal agenda exists where ‘specialist’ knowledge is conferred by health care professionals who do not ‘need’ to draw on POONSs’ knowledge. These personal agendas are referred to as peer-driven agendas. In the main, these exist for senior, hospital-based health care professionals at regional centres, who, in the absence of POONSs, could (and previously did) provide a skeleton outreach service to children being cared for locally. In this scenario, ‘specialist’ is denoted by the attributes which distinguish one ‘specialist’ from another. However, peer-driven agendas also exist for senior medical staff, regardless of their work location, whose concerns include the professional well-being of POONSs. It is these two peer-driven agendas which are the focus of this section of the chapter.
(1) Distinguishing Between 'Specialists':

A major characteristic of peer-driven agendas concerns distinguishing between 'specialists'. This arises from two perspectives: firstly it occurs when senior hospital-based health care professionals at regional centres distinguish the 'specialist' nature of POONSs work as distinct from either their own, or that of other senior hospital staff. Secondly, it transpires when health care professionals across both community and acute hospital settings distinguish the 'specialist' nature of POONSs' knowledge from that of PCNs.

Senior health care professionals at regional centres achieve their own 'specialist' status such that both consultants and sisters develop their own 'specialist' areas of practice including bone marrow transplantation, long-term follow-up, adolescence and disease-specific areas. In this situation 'specialist' knowledge is constructed amongst peers of POONSs as that which distinguishes the nature of POONSs work from their own, or that of other senior staff. In the main, 'specialist' knowledge is construed around the backgrounds of both the POONSs they work with and, for some, POONSs at other regional centres; it is reflected in post-basic qualifications and work experience, particular to POONSs (Figure 10.1). One sister expressed this by saying:

*the people I've worked with are people who've had a community background and paediatric training plus oncology.... to me it appears to work well so therefore I feel that is what they need*

(Sr4, Southern Regional Hospital)

In this peer-driven agenda there is an axiom amongst sisters and consultants that all senior nursing staff have attained previous work experience and formal training in paediatrics and oncology. The formal training and work experience which distinguishes POONSs' 'specialist' knowledge from that of their nursing peers, as suggested above, concerns community nursing work:

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3 Through the professional bodies of PONF and the UKCCSG, several senior staff at regional centres have global insight into POONSs' backgrounds.
I think there is a dimension to care in the community which we who work in hospital don't understand

(Consultant 5, Northern City Hospital)

Not only is great emphasis placed upon formal training and 'specialist' work experience in community nursing but this type of agenda uniquely recognises the importance of POONSs in-depth, 'specialist', 'medical' knowledge. It is this in-depth 'medical' knowledge which distinguishes the 'specialist' knowledge of POONSs from that of consultants. Here, consultants and sisters alike, overtly recognise that POONSs' 'specialist', 'medical' knowledge lies in symptom management during terminal care which exceeds the knowledge of consultants. One commented:

*nearly always they (POONSs) know more about pain control than the doctors do, they have a much better feel for it... beyond sort of straightforward anti-emetics, you know, they're usually very good on second and third line anti-emetics*

(Consultant 7, Southern Regional Hospital)

A second feature which distinguishes POONSs from other 'specialists', contributing towards a peer-driven agenda, determines the 'specialist' nature of POONSs from PCNs. This arises when health care professionals across community and acute hospital sectors have experience working with both groups of outreach nurses. Whilst it is formal training and experience in community nursing which stands POONSs apart from hospital-based health care professionals at regional centres, it is community nursing which draws the specialist nature of POONSs and PCNs together. However, there are components of conferred 'specialist' knowledge which distinguish POONSs from PCNs. The different experiences of PHCTs and acute-hospital staff mean that professionals across the two health care sectors draw on different components of conferred 'specialist' knowledge to distinguish the specialist nature of POONSs.

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4 The Southern Regional Hospital is located in a region which is particularly well served by PCN teams. These services remain scant in more northern regions of the country and in areas where CLIC nursing services operate (Whiting 1995).
PHCTs predominantly distinguish the ‘specialist’ nature of POONSs work from PCNs through hands-on technical skills. Whilst they acknowledge that both possess ‘specialist’ technical skills relative to their own, the skills of POONSs are perceived to be more ‘specialist’ than those of PCNs. Hospital-based health care professionals on the other hand, distinguish POONSs from PCNs because of their formal qualifications, previous ‘specialist’ work experience and in-depth ‘medical’ knowledge. One hospital doctor said: ‘[POONSs] are likely to have had to have done more, longer, specialist training (than PCNs)’ (SHO 3, Southern Regional Hospital), whilst a consultant commented: ‘I don’t know how they (PCNs) get trained but I assume as part of their training they wouldn’t have a lot of emphasis put on how you manage a child dying of cancer at home’ (Consultant 6, Southern Regional). The differences in formal training, specialist work experience and hands-on tasks are confirmed by a PCN interviewed during the course of this study who said:

nurses in that specialty usually have gone through courses for blood-letting and, you know, the practical things

(PCN2, Southern Regional area)

(2) The Professional Well-Being of POONSs:
A second peer-driven agenda concerns the professional well-being of POONSs. This feature of conferred ‘specialist’ knowledge is predominantly associated with senior hospital doctors who assume a level of responsibility for the professional welfare of POONSs. The reasons why these perceived responsibilities arise are unclear. However, they are particularly developed in consultants who have procured charitable funds to establish POONS services. In this instance, consultants appear to maintain a vested interest in the well-being of POONSs to ensure the success of the service. The concerns for the professional well-being of POONSs, which steer this peer-driven agenda, arise firstly from the perceived ‘specialist’ knowledge required to establish successful relationships with local communities. Secondly, they exist for district-based consultants concerned that POONSs maintain professional credibility through sustaining ‘specialist’ knowledge.
Regional consultants, concerned for the professional well-being of POONSs, are troubled by relationships between POONSs and local communities. In this scenario, professional well-being, it is assumed by consultants, is gained through credibility with community nurses. This is achieved through POONSs accomplishing community nursing qualifications. Here, it is anticipated that POONSs require a community nursing qualification to make: 'them (POONSs) more acceptable to the local people' (Consultant 6, Southern Regional Hospital) and 'to the local paediatric teams' (Consultant 7, Southern Regional Hospital). Credibility as a 'specialist' is then established when, it is perceived, the post-basic qualifications of POONSs both match and exceed those of community nurses. In this agenda great value is placed on post-basic formal qualifications (Figure 10.1).

Concerns for the professional well-being of the CLIC nurse at Westlands, by consultants, take a different form. Here, sustaining and up-dating acquired knowledge is required in order to establish credibility amongst hospital-based health care professionals, thereby maintaining a 'specialist' status. In the main, this concerns keeping up-to-date with hands-on technical skills. When it is perceived that hands-on skills are kept up-to-date, professional credibility, 'specialist' status and consequently professional well-being is maintained. As one consultant commented:

she's very good at going off and going into all the sessions and so forth
(Consultant 2, Westlands District Hospital)

In summary, 'specialist' knowledge is conferred on POONSs by other health care professionals in relation to two personal agendas: needs-driven agendas and peer-driven agendas. There are several needs around which health care professionals construct a 'specialist'. These include: gaps in knowledge, personal anxieties around caring for children with malignant disease and the needs of SNs pursuing careers. Peer-driven agendas are derived from two areas. Firstly, they are built around the distinctions health care professionals draw between 'specialists'. Here, senior, regional hospital staff discern between the 'specialist' nature of POONSs work and other oncology 'specialists'. Also, both hospital and community staff distinguish
between POONSs and PCNs. Secondly, they are derived from senior hospital doctors' concerns about the professional well-being of POONSs.

The 'Right' Personality

_I think with regards to actually caring for the patient.... you're either good at doing it or you're not_  
(PCN1, Southern Regional area)

In addition to their own personally-driven agendas of a 'specialist', most health care professionals suggest it is imperative that a POONS has the 'right' personality. The 'right' personality for the job is universally important to all those who work with POONSs, both in hospitals and the community. There are three main reasons for this. Firstly POONSs, particularly those at regional centres, are seen by hospital colleagues as 'ambassadors' for their units. Secondly, hospital staff recognise that POONSs have a major role in communicating across the primary, secondary and tertiary interface - they encounter a diverse group of health care professionals which requires good interpersonal skills. Thirdly, all health care professionals working with POONSs recognise the 'special' bonds which families develop with POONSs. These bonds similarly command good interpersonal skills, including tact and diplomacy. They also require 'mature' personalities to cope with the demands of paediatric palliative care.

Common to all health care professionals working with POONSs, important personality traits include the ability to be 'composed' and 'approachable'. The sentiments about the 'right' personality for the job are typically expressed by one consultant who commented:

_I would want to know that these are people who are rounded, who are capable of good inter-personal skills, who can absorb a certain amount of stress without freaking out_  
(Consultant 5, Northern City Hospital)
Nevertheless, there are discernible differences between the ways in which regional, hospital-based health care professionals perceive the 'right' personalities of POONSs, compared to those working at Westlands. POONSs at regional centres are expected to have assertive personalities with leadership, organisational and competency skills frequently being attributed to them. One consultant went so far as to suggest that POONSs require an intellect which exceeds that of other nursing staff. He said:

.....it (the POONS's role) would attract very bright, competent people and what one wants to attract is people who are caring, clever and capable and willing to use initiative because I think that's in the best interest of the families... one imagines that the role would have had sufficient responsibility and flexibility to encourage bright and intelligent people to stay within it

(Consultant 1, Moorcroft Children's)

Staff at Westlands, on the other hand, expected more passive traits of POONSs. This point is exemplified by one SN who suggested POONSs need: 'to be interested and.... enjoy looking after these children' (SN6, Westlands District Hospital). The reasons different attributes are expected of regional and district-based POONSs are unclear. However one answer may lie in the influences of charities' strategies on approaches to care. It is possible that POONSs who adopt 'hands-on' approaches to care incline towards submissive personalities. In contrast, it is likely that nurses with more assertive personalities incline towards a 'hands-off' or mixed 'hands-on/hands-off' method of work (Hunt 1995). Whatever, the reason for these differences, the personalities of all POONSs are of paramount importance to the health care professionals they work with.

Conclusion

This chapter has addressed 'specialist' knowledge. In so doing, it has suggested firstly, that there are professionally-driven agendas which demand that CNSs are highly experienced and trained beyond registration. The divergent strategies adopted by the charities funding POONS posts have resulted in MPNs and 'Mixed Funders' POONSs generally fulfilling these requirements, whilst CLIC nurses are less likely to. Secondly, it has been contended that, in the main, health care professionals ignore professionally-driven agendas and construct 'specialist' knowledge according to their
own experiences and agendas. These personal agendas are dependent upon the level of experience individual health care professionals have themselves gained in childhood malignancy, the hospital location of the POONS/s with whom they work and the professional backgrounds of particular POONS/s. Two personal agendas have been discussed: needs-driven agendas and peer-driven agendas. These have drawn upon formal qualifications, hands-on technical skills, 'specialist' work experience, in-depth 'medical' knowledge and insight into families' dynamics (Figure 10.1). The relative contribution each of these 'knowledge' components make to conferring 'specialist' status on POONSs within these two agendas, are primarily dependent upon the regional or district location of POONSs. This chapter has argued that the work location of POONSs (in turn influenced by the strategies funding their posts) has contributed towards: 'All POONSs being specialists, some POONSs being more specialist than others'. However, regardless of how 'specialist' status is conferred, of paramount importance to health care professionals, are POONSs' personalities. The degrees to which health care professionals' perceptions of 'specialist' knowledge impact on their professional relationships with POONSs are the focus of the following two chapters.
Introduction

A complex system of health care has evolved to manage childhood malignancy in which care is shared between interdisciplinary health care professionals across primary, secondary and tertiary health care settings (Chapter Two). This results in a complex communication network in which POONSs play a pivotal role to provide a 'seamless web of care' (Bignold et al. 1995a). Relationships developed between POONSs and other health care professionals consequently play a crucial part in enhancing shared patient care across these three settings. How these relationships are constructed and how they are affected by the mixed funding sources (i.e. 'Funder' models) of POONSs are the focus of the next two chapters.

In this study relationships developed between POONSs and other health care professionals varied and were dependent upon three factors. Firstly relationships varied according to the location of health care professionals working with POONSs. POONSs worked closely with different professional groups across two settings: the acute hospital environment and the community. It is the relationships between POONSs and community health care professionals which are the focus of this chapter. For PHCTs contact with POONSs is usually restricted to the sharing of care for one particular patient. Relationships between POONSs and PHCTs are often transient, dissolving upon the death of a child. However for HVs who might anticipate future children with malignant disease on their caseloads, and GPs who choose to have greater involvement in bereavement care, relationships with POONSs may be more lasting. Understandably different relationships between POONSs and hospital-based colleagues (whether regional or district-based) exist; hospital staff have day-to-day contact with POONSs and greater knowledge of childhood malignancy than PHCTs.

Secondly relationships developed with hospital-based colleagues were dependent upon the level of seniority of hospital staff; POONSs formed different relationships with senior doctors and nurses than with junior staff (see Chapter Nine). Relationships
between POONSs and hospital-based health care professionals are discussed in Chapter Twelve. Thirdly, and linking the above two factors, differences existed in professional relationships between POONSs and other health care professionals due to the district or regional locations of POONSs and thus the strategies adopted by charities funding their posts.

This chapter, the first of two exploring professional relationships, constructs a relationship typology between POONSs and PHCTs. ‘Empowerment’ and ‘partnership’ are used to develop a framework for understanding relationships with PHC professionals. The chapter draws on data from both stages of the research to suggest that the greatest differences in relationship types occurs between POONSs based at regional children’s cancer treatment centres (associated with the Macmillan and the ‘Mixed Funders’ models) and those at DGHs, predominantly the CLIC-funded POONSs.

It is acknowledged that individual POONSs will develop their own working styles. Nevertheless, it is contended that the divergent strategies adopted by the two main charities funding POONSs, impact upon the type of relationship that develops between POONSs and PHCTs. Three distinct types of relationship developed between POONSs and PHCTs. Firstly an ‘empowerment’ type exists where POONSs work with PHCTs, teaching them, thereby enabling them to actively participate in the care of children with malignant disease, more particularly during terminal care. The research data suggests this to be more commonly associated with POONSs who provide ‘hands-off’ care, working at regional centres. It is more especially associated with the Macmillan model and is in keeping with CRMFs’ ideals.

Secondly a ‘partnership’ type evolved in which POONSs work closely with PHCTs, retaining much care of terminally ill children themselves, but forming close links with PHCTs during the early days of a child’s diagnosis. This, the data suggests is closely related to the ‘Mixed Funders’ model where both a ‘hands-on’ and a ‘hands-off’ type of care is adopted, reflecting the contrast in practices within this ‘Funder’ group.
Thirdly a 'disempowerment' type arose in which POONSs maintain more limited contact with PHCTs, informing them but rarely sharing skills or seeking their active participation in a child's care. Here 'hands-on' care is retained by POONSs. This was most commonly identified with the CLIC model and reflects CLIC's philosophy to provide 'direct' care (Bignold et al. 1994a). A fourth less distinct relationship type exists in which the boundaries between 'partnership' and 'empowerment' are blurred. This reflects both the difficulties in distinguishing between the two concepts (Chapter Four) and the similar regional locations of POONSs associated with both the Macmillan and the 'Mixed Funders' model. Features of the relationship typology have been summarised in Table 11.1.

An 'Empowerment' Relationship

This section examines the concept of 'empowerment' in relation to PHCTs' relationships with POONSs. More particularly it explores how the mixed economy of health care, which has influenced the development of the three 'Funder' models, affects the construction of 'empowerment'. It will examine how 'empowerment' is achieved and why POONSs affiliated to one 'Funder' model (i.e. the Macmillan model) primarily 'empower' professionals working in primary care, whilst POONSs associated with other 'Funder' models construct different relationship types. It will be argued that the philosophies adopted by CRMF influence the construction of an 'empowerment' type of relationship.

The rarity of childhood malignancy and the anxiety which this creates inevitably means that PHCTs are unable to provide the specialised care required to support children at home unless they are 'empowered' by expert practitioners, such as POONSs. Implicit in the nature of 'hands-off' nursing care, which, it was argued in Chapter Six was most closely identified with the Macmillan model, is the notion of 'empowerment'. POONSs identified with the Macmillan model have demonstrated their ability to empower PHCTs in a number of ways and components of this relationship type are the focus of this discussion.
Table 11.1 Summary of the ‘Partnership/Empowerment/Disempowerment’ Typology

**Empowerment:**
- PHCTs taught clinical skills
- DNs more involved in decision-making processes during child’s terminal care
- ‘Moderate’ levels of communication, facilitated by ‘on-call’

**Partnership:**
- HVs visited by POONSs to develop professional relationships
- DNs given access to newly diagnosed children
- Greater contact generally between HVs and POONSs
- GPs offered visits to discuss newly diagnosed children

**Mixed Partnership/Empowerment:**
- Planned approach to discharging/referring patients for terminal care
- DN access to patients facilitated
- Face-to-face contact established during terminal care
- HVs retain/gain decision-making powers

**Disempowerment:**
- Fewer DNs involved in patient care
- Poorer relationships developed between DNs and families
- Fewer visits or phone calls to all PHCT members
- Inconsistent contact with GPs at outset of illness
- No participation of GPs to plan terminal care
- Less face-to-face contact with DNs & GPs
- Crisis intervention contact with HVs
- HVs & DNs ‘intrude’ on relationships established between POONSs and families

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Teaching and Learning ‘Specialist’ Skills

A major feature of ‘empowerment’ involves PHCTs acquiring ‘specialist’ skills. The research suggests this most commonly refers to handling CVADs (usually Hickman lines) and gaining knowledge about symptom control during terminal care. Evidence from the POONS data set suggests that MPNs more commonly reported visiting PHCTs to teach these skills (Table 11.2). They also more commonly visited GPs to offer advice on terminal care (Table 11.2(c)). Being taught clinical skills affects the abilities of PHCTs to become decision makers and reduces the necessity for excessive contact with POONSs. Both enabling PHCTs to become decision-makers and degrees of communication between PHCTs and MPNs are discussed in detail below.

Becoming Decision-Makers during Terminal Care

Enabling PHCTs to make decisions about care may occur at the onset of a child’s disease (see ‘Partnership/Empowerment’). More commonly however it arises when the focus of a child’s care switches from the hospital to the community i.e. during terminal care. Here DNs are ‘empowered’ to become decision makers. This was particularly evident amongst DNs working within the Northern City catchment area. Here DNs considered that POONSs made major decisions about changing drugs or dosages; nevertheless they were ‘empowered’ to provide the daily care required to make small modifications to drug dosages and change syringes of morphine for intravenous administration¹. As one DN stated:

*I mean towards the end [MPN 1] wasn’t actually involved as much with us ’cause once we got him pain controlled -*

(DN4, Northern City area)

¹ Whilst a few DNs reported some previous experience of managing Hickman lines none were familiar with intravenous administration of morphine which is a commonly recognised route in paediatric terminal care.
<table>
<thead>
<tr>
<th>FUNDER MODEL</th>
<th>Macmillan (N=5)</th>
<th>CLIC (N=10)</th>
<th>‘M.F.’* (N=28)</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Teaching/Advising:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Skills</td>
<td>2 (40%)</td>
<td>1 (11%)</td>
<td>5 (18%)</td>
<td>8 (19%)</td>
</tr>
<tr>
<td>Terminal Care</td>
<td>1 (20%)</td>
<td>2 (22%)</td>
<td>7 (25%)</td>
<td>9 (21%)</td>
</tr>
<tr>
<td>New Pts./On treatment</td>
<td>1 (20%)</td>
<td>1 (11%)</td>
<td>7 (25%)</td>
<td>8 (19%)</td>
</tr>
<tr>
<td><strong>Conducting Joint Visits</strong></td>
<td>-</td>
<td>-</td>
<td>8 (29%)</td>
<td>8 (19%)</td>
</tr>
<tr>
<td><strong>Developing Professional Relationships</strong></td>
<td>3 (60%)</td>
<td>3 (33%)</td>
<td>19 (68%)</td>
<td>25 (60%)</td>
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### (b) Purpose of Visits to HVs

<table>
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<th>FUNDER MODEL</th>
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<th>‘M.F.’* (N=28)</th>
<th>TOTAL</th>
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<tbody>
<tr>
<td><strong>Teaching/Advising:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Skills</td>
<td>1 (20%)</td>
<td>-</td>
<td>2 (7%)</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>Terminal Care</td>
<td>-</td>
<td>-</td>
<td>1 (3%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>New Pts./On treatment</td>
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<td>-</td>
<td>15 (54%)</td>
<td>15 (36%)</td>
</tr>
<tr>
<td><strong>Developing Professional Relationships</strong></td>
<td>2 (40%)</td>
<td>3 (33%)</td>
<td>20 (71%)</td>
<td>25 (60%)</td>
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### (c) Purpose of Visits to GPs

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<th>CLIC (N=10)</th>
<th>‘M.F.’* (N=28)</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Teaching/Advising:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Skills</td>
<td>1 (20%)</td>
<td>1 (10%)</td>
<td>1 (3%)</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>Terminal Care</td>
<td>4 (80%)</td>
<td>2 (20%)</td>
<td>17 (61%)</td>
<td>23 (53%)</td>
</tr>
<tr>
<td>New Pts./On treatment</td>
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<td>-</td>
<td>9 (32%)</td>
<td>9 (21%)</td>
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<tr>
<td><strong>Developing Professional Relationships</strong></td>
<td>2 (40%)</td>
<td>3 (30%)</td>
<td>11 (39%)</td>
<td>16 (37%)</td>
</tr>
</tbody>
</table>

* Includes Public Health Nurses from Eire
N.B. Figures exceed 100%: not all POONSs visited PHCTs, others gave more than 1 response
The Effects of Communication on ‘Empowerment’

Communication between PHCTs and POONSs is crucial to the development of and distinctions between the ‘empowerment/partnership/disempowerment’ typology. It therefore follows that the degree and nature of contact between POONSs and DNs, HVs and GPs is a major component in the development of an ‘empowerment’ relationship. ‘Empowerment’ results in ‘handing over’ components of care once ‘specialist’ skills have been learnt. Hence it follows that a feature of ‘empowerment’ concerns the degree of communication between POONSs and PHCTs - the necessity for POONSs to maintain contact with PHCTs, once empowered, may be minimised.

POONSs associated with the Macmillan model suggested ‘moderate’ levels of communication between themselves and PHCTs through the telephone calls and visits to health centres which they made (Tables 11.3 & 11.4). In other words, although similar numbers of ’phone calls were made to DNs and HVs by POONSs associated with both the CLIC and the Macmillan models (Tables 11.3 (a),(b)), more ’phone calls were made to GPs by MPNs than CLIC nurses (see Table 11.3 (c)). In addition, more visits were made to all PHCT members by MPNs than POONSs identified with the CLIC model but fewer compared with those identified with the ‘Mixed Funders’ model (Table 11.4). Hence POONSs associated with the Macmillan model had ‘moderate’ contact with PHCTs compared to POONSs associated with the other two ‘Funder’ models: ‘moderate’ levels of communication between POONSs and PHCTs are thus a feature of an ‘empowerment’ typology.

Secondly, ‘empowerment’ is achieved when communication is aided by the provision of an on-call service. Although most POONSs provided on-call services, the ways in which these services functioned varied (see Chapter Six). ‘Empowerment’ is accomplished through the provision of a 24 hour on-call service to PHCTs; it enables PHCTs to make immediate contact with POONSs should they be contacted by parents or encounter a situation with which they are unfamiliar. They then gain the information and confidence on which to act and are thus ‘empowered’ to provide that care. This component of ‘empowerment’ is again most apparent in CRMF-funded services; it particularly benefitted two-way communication between DNs working in the Northern City area and MPNs:
Table 11.3 (a),(b),(c) Calls to PHCTs during preceding month, comparing 'Funder' Models

<table>
<thead>
<tr>
<th>(a) No. of Calls to DNs</th>
<th>FUNDER MODEL</th>
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<th></th>
</tr>
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<td>CLIC</td>
<td>'M.F.'*</td>
</tr>
<tr>
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<td>2 (50%)</td>
<td>4 (44%)</td>
<td>5 (18%)</td>
</tr>
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<td>1 - 5</td>
<td>2 (50%)</td>
<td>4 (44%)</td>
<td>11 (39%)</td>
</tr>
<tr>
<td>6 - 10</td>
<td>-</td>
<td>1 (11%)</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>11 - 15</td>
<td>-</td>
<td>-</td>
<td>3 (11%)</td>
</tr>
<tr>
<td>16 - 40</td>
<td>-</td>
<td>-</td>
<td>5 (18%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>9^1 (100%)</td>
<td>28^2 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(b) No. of Calls to HVs</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
<th></th>
</tr>
</thead>
<tbody>
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<td>Macmillan</td>
<td>CLIC</td>
<td>'M.F.'*</td>
</tr>
<tr>
<td>None</td>
<td>1 (25%)</td>
<td>2 (22%)</td>
<td>4 (14%)</td>
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<tr>
<td>1 - 5</td>
<td>2 (50%)</td>
<td>6 (67%)</td>
<td>16 (57%)</td>
</tr>
<tr>
<td>6 - 10</td>
<td>1 (25%)</td>
<td>1 (11%)</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>11 - 20</td>
<td>-</td>
<td>-</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>over 20</td>
<td>-</td>
<td>-</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>4^1 (100%)</td>
<td>9^1 (100%)</td>
<td>28^2 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(c) No. of Calls to GPs</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
<th></th>
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<td>CLIC</td>
<td>'M.F.'*</td>
</tr>
<tr>
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<td>-</td>
<td>3 (33%)</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>1 - 5</td>
<td>3 (75%)</td>
<td>4 (44%)</td>
<td>10 (36%)</td>
</tr>
<tr>
<td>6 - 10</td>
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<td>5 (18%)</td>
</tr>
<tr>
<td>11 - 15</td>
<td>-</td>
<td>2 (22%)</td>
<td>-</td>
</tr>
<tr>
<td>TOTAL</td>
<td>4^1 (100%)</td>
<td>9^1 (100%)</td>
<td>28 (100%)</td>
</tr>
</tbody>
</table>

* See List of Abbreviations

1 Incomplete response to question

2 Includes calls made to Public Health Nurses from Eire
Table 11.4  (a), (b), (c) Visits to PHCTS during preceding month, comparing 'Funder' Models

<table>
<thead>
<tr>
<th>(a) No. of Visits to DNs</th>
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<td>3 - 4</td>
<td>1 (20%)</td>
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</tr>
<tr>
<td>5 - 8</td>
<td>1 (20%)</td>
<td>-</td>
</tr>
<tr>
<td>over 8</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>9\textsuperscript{1} (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(b) No. of Visits to HVs</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
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<tr>
<td>None</td>
<td>3 (60%)</td>
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<td>1 - 2</td>
<td>1 (20%)</td>
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<td>3 - 4</td>
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<td>1 (11%)</td>
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<tr>
<td>5 - 8</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>over 8</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>9\textsuperscript{1} (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(c) No. of Visits to GPs</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
</tr>
<tr>
<td>None</td>
<td>1 (20%)</td>
<td>4 (44%)</td>
</tr>
<tr>
<td>1 - 3</td>
<td>3 (60%)</td>
<td>5 (55%)</td>
</tr>
<tr>
<td>4 - 6</td>
<td>1 (20%)</td>
<td>-</td>
</tr>
<tr>
<td>7 - 9</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (100%)</td>
<td>9\textsuperscript{1} (100%)</td>
</tr>
</tbody>
</table>

\textsuperscript{*} See List of Abbreviations

\textsuperscript{1} Incomplete response to question

\textsuperscript{2} Includes Public Health Nurses from Eire

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quite often I used to ring her in the morning, if she got a phone call from (the family) at night and there was a problem she'd ring me first thing in the morning.... she'd let me know straight away, if I'd heard from (mum) that night that there'd been a problem, I'd ring [MPN 1]

(DN2, Northern City area)

I suppose I knew that I could get hold of [MPN 2] if I'd got a problem in the last couple or three weeks and by that time I had got to know her well enough to sort of phone her and say, 'I can't cope with this, can you sort of come out', so I had as much contact with her as I felt I needed I suppose

(DN3, Northern City area)

Hence 'empowerment' is achieved through communication with POONSs: it evolves through 'moderate' levels of contact from POONSs and through the availability of a 24 hour service to PHCTs. Both of these are associated with MPNs, linking Macmillan with this type of relationship. Since it is CRMF's policy to suggest that MPNs work in collaboration with other health care professionals (CRMF 1995) enabling them to be the main providers of care (CRMF 1992), it might be assumed that CRMF directly influence the construction of an 'empowerment' relationship type through influencing levels of communication between PHCTs and POONSs.

Effects of Empowerment on PHCTs
The process of 'empowerment' is an enriching experience for PHCTs. Whilst many interviewed during the course of this study started off feeling anxious about caring for dying children, those who developed an 'empowerment' relationship with POONSs experienced a sense of satisfaction through their own achievements. They were also rewarded by the close relationships developed with families. It enabled them as Gibson (1995) suggested, to solve problems and to gain a sense of control in the care being provided. One DN who had had a particularly difficult time, working with a family unable to accept the impending death of their child, summed up her experiences thus:

the experience...was not a pleasant one except I'm really pleased I got the opportunity to work with [MPN 3]... and who knows maybe we'll work together in the future

(DN5, Northern City area)
In summary, this research suggests that 'empowerment' is attained through three main characteristics: it is achieved through handing over 'specialist' skills which in turn develop decision-making abilities; these in turn affect the levels of communication which exist between POONSs and PHCTs; communication is itself facilitated by the provision of a 24 hour on-call service. These traits are summed up in Table 11.1. The findings from this study suggest that features of 'empowerment' are most commonly associated with MPNs.

**A ‘Partnership’ Relationship**

A ‘partnership’ relationship differs from ‘empowerment’ in that some components of care, particularly during a child’s terminal illness, are retained by POONSs, rather than handed over. Furthermore ‘partnerships’ evolve at an early stage of a child’s ‘cancer journey’ rather than at the onset of a child’s terminal illness. ‘Partnership’ relationships exist between PHCTs and POONSs when a ‘mixed’ type of nursing is practised where POONSs provide both ‘hands-on’ and ‘hands-off’ nursing care. The flexible strategies adopted by charities associated with POONSs affiliated to the ‘Mixed Funders’ model resulted in both approaches to nursing care, and thus a ‘partnership’ type of relationship being adopted by POONSs identified with the ‘Mixed Funders’ model. This is demonstrated in a variety of ways and is discussed in this section of the chapter. Features of ‘partnership’ are summarised in Table 11.1.

**Communication between PHCTs and POONSs in a ‘Partnership’ Relationship**

It was suggested above that communication plays an important role in distinguishing between ‘partnership’, ‘empowerment’ and ‘disempowerment’. It follows therefore that there are features of communication between POONSs and PHCTs which relate to a ‘partnership’ relationship type. A mixed ‘hands-on’ and ‘hands-off’ approach to care, particularly during a child’s terminal illness, facilitates PHCTs to provide some care to patients whilst the majority is retained by POONSs. It follows therefore that frequent communication need exist between POONSs and PHCTs in order that health care professionals know who is doing what. Therefore a feature which links POONSs associated with the ‘Mixed Funders’ model to a ‘partnership’ relationship concerns the levels of communication which arises between themselves and PHCTs. POONSs
linked with the 'Mixed Funders' model made more 'phone calls and visits to PHCTs than POONSs associated with the other two 'Funder' models (Tables 11.3 & 11.4). They also conducted joint home visits with DNs thereby having increased opportunities for face-to-face contact (Table 11.2 (b)). Hence conducting joint visits with DNs and maintaining 'high' levels of communication with all PHCT members through visits and calls are a feature of a 'partnership' relationship type.

A second distinguishing feature of communication between POONSs and PHCTs in a 'partnership' relationship concerns contact with HVs. In 'partnership' greater levels of communication exist between POONSs and HVs throughout a child’s illness, compared to other relationship types. From the POONS data set it was evident that POONSs identified with the 'Mixed Funders' model had the most contact with HVs (Tables 11.2 (b), 11.3 (b) & 11.4 (b)). In particular visits were made to establish 'partnerships' following a child’s diagnosis and were maintained throughout chemotherapy treatment (Table 11.2 (b)). Few HVs were interviewed in the Northern City region (Tables 7.1 & 8.1). There is no way of knowing whether POONSs attached to the Southern Regional saw more preschool aged children than those at the Northern City or whether they placed greater emphasis on HVs’ roles. Nevertheless that more HVs in the Southern Regional area were interviewed was indicative of greater contact between POONSs and HVs in the 'Mixed Funders' model.

Although greater contact is maintained between POONSs and HVs in a 'partnership' compared to other relationship types, frustration may be exhibited if HVs needs are not fully met (see Chapter Eight). This was particularly the case for HVs who had experience working with Liaison HVs in local hospitals. An example of this was demonstrated by a HV in the Southern Regional catchment area who would have preferred more communication than she received:
It would perhaps be helpful to know either by a quick phone call or something, that she's had one lot of treatment and has come home, because I'm never sure when she's in and when she's home.... I checked the notes and I found out she was in... as I say, if it was just a quick phone call, you know, to say that Lucy's been in for ten days and she's now home again and due to come back on such-and-such a day

(HV12, Southern Regional area)

In summary, a feature of 'partnership' concerns greater levels of communication between POONSs and PHCTs compared to an 'empowerment' relationship. In particular communication is maintained with HVs throughout a child's treatment. Although not always at a level desired by HVs, as shown later in this chapter, this type of relationship is preferable to one in which HVs are disempowered.

**Forging Relationships at the Outset of the 'Cancer Journey'**

A key characteristic of the 'partnership' typology which is closely linked to communication, concerns the establishment of professional relationships with PHCTs at the outset of a child's 'cancer journey'. Here POONSs provide visits to health centres once a child's diagnosis has been established and the treatment regimen instigated. This allows for a mutual exchange of information and recognises that GPs and HVs have often had long standing relationships with families prior to a child's diagnosis. Forging relationships with HVs has already been highlighted above through the levels of communication which exist.

Another example arises when DNs are involved in patient care at an early stage in a child's cancer journey. In this study DNs were generally referred children who were terminally ill, often for specific task-related purposes; they were usually dependent on POONSs to gain access to patients (see Chapter Eight). Where a 'partnership' relationship is established, access is 'permitted' to DNs by POONSs at the outset of a child's illness trajectory rather than at the onset of terminal care. With the exception of one DN in the Northern City area who was referred a newly diagnosed child with a multiplicity of nursing problems, referrals of newly diagnosed children were confined to DNs working with POONSs from the Southern Regional Hospital. Although early referrals to DNs were appreciated as a building block on
which to develop future working relationships: 'this was just an introduction to build ships on' (DN15, Southern Regional area), they were sometimes considered unnecessary either because the parents themselves were eventually taught to do the tasks for which they had been referred, the DNs were not skilled (or permitted by the restraints of local policies) in the tasks being required of them (usually Hickman line care) or the referral became superfluous:

[POONS 1] was going to contact me if there was any problem about the chemotherapy at home..... we weren't informed whether the girl was home or not, so we assumed in fact that we wouldn't be involved because we didn't know you know, they'd contact us if there was an input from us

(DN15, Southern Regional area)

DNs and HVs may question either the necessity of a child’s referral or the degrees of contact between themselves and POONSs in a ‘partnership’ relationship. However a child’s long-term outlook, however curable their disease, remains uncertain for months or years to come. Therefore forging links with POONSs at the earliest given opportunity, as will be demonstrated through a ‘disempowerment’ relationship, benefits both families and professional relationships.

Another characteristic involves forging relationships with GPs. Again, this was most commonly linked to POONSs identified with the ‘Mixed Funders’ model. Only POONSs in this group reported visiting GPs at the outset of a child’s disease to discuss diagnosis, prognosis, treatment and the effects of childhood malignancy on families (Table 11.2 (c)). Substantiating this, GPs working within the Southern Regional area more commonly talked of visits by POONSs at this time.

Relationships between GPs and families are often well established prior to a child’s diagnosis (see Chapter Eight). Prior relationships with families along with previous experience working with CNSs in other fields influenced GPs responses to visits from POONSs. One GP for example who had a long standing relationship with a family in her care, considered that the POONS’s visit enabled her: ‘to ask silly questions like “what’s a Hickman line” and whatever’ (GP21, Southern Regional area). Another GP
however considered that the child’s parents, who he also knew well, were happy with the treatment and their child’s progress. The offered visit by the POONS therefore wasn’t: ‘necessary at that stage’ (GP20, Southern Regional area).

GPs in this study had frequently been contacted by POONSs at the outset of a child’s disease and, regardless of the type of relationship formed, most valued ‘phone calls from POONSs. Without face-to-face contact however, some GPs had difficulty remembering the information they had been given, many recognising POONSs had had little impact on their practice. Indeed several questioned the value of such conversations. As one GP explained: ‘remembering the existence of these people.... and registering change is something that the human brain has difficulty with’ (GP12, Northern City area). Therefore a ‘partnership’ relationship only develops when POONSs offer to visit GPs at their surgeries or if face-to-face contact with POONSs is established. When this does not occur rapport does not develop between POONSs and GPs, hindering the development of a ‘partnership’.

Recapitulating, a key feature which constitutes ‘partnership’ relationships concerns forging relationships with PHCTs at an early stage in a child’s disease. This is synonymous with ‘high’ levels of communication, particularly with HVs, throughout a child’s cancer journey, offering visits to GPs surgeries shortly after a diagnosis has been confirmed and referring children to DNs during the early days.

A Mixed ‘Partnership/Empowerment’ Relationship

The literature has suggested that ‘partnership’ and ‘empowerment’ are often intertwined (e.g. Darbyshire & Morrison 1995, Gormley 1996, Rudman 1996, Sully 1996, Taylor 1996). Thus far this chapter has suggested discernable characteristics between the two concepts. Nevertheless, it is proposed that there are ‘grey areas’ which make further distinctions difficult. This led to the emergence of a combined ‘partnership/empowerment’ type of relationship, the characteristics of which are discussed in this section of the chapter.
Planning Referrals

An example of the indiscriminateness between 'partnership' and 'empowerment' concerns a planned approach to referrals and discharging children home from hospital for terminal care. Data from the second stage of the research suggest that both 'partnership' and 'empowerment' relationships, developed during a child's terminal illness, are marked by meetings (usually multidisciplinary - including DNs and GPs) at health centres. These meetings (often referred to as case conferences) are planned by POONSs prior to or around the time of a child's discharge from hospital (see Chapter Eight). They were discussed by PHCTs at both regional case study sites and are epitomised by the following:

(the referral) was probably a month before Lynette was due to come actually home and there was, there was a sort of contact on and off during this month with updates and things

(DN9, Southern Regional area)

I was basically contacted early on before it got to crisis proportions and that worked very well, to be contacted from Northern City saying, 'this is my role, can I come and talk to you?' and... which she did

(GP3, Northern City area)

[POONS 1] contacted me and asked to meet myself, I job-share, and [colleague] to meet her with the GP, so that was the first contact was through [POONS 1] on the phone and then we had a meeting with myself and [colleague] and [GP] and [POONS 1] at the surgery

(DN10, Southern Regional area)

She phoned me up to introduce herself.... while Polly was still an inpatient in the Southern having her radiotherapy, so in fact it was very early on

(GP 9, Southern Regional area)

In a mixed 'partnership/empowerment' relationship this often occurs whether or not it is envisaged DNs have an active role to play:

[MPN 2] made this referral to us by way of saying, 'you won't be needed but the family would just like to know that you're around'

(DN3, Northern City area)
Communication in a Mixed ‘Partnership/Empowerment’ Relationship

There are distinct communication differences between ‘empowerment’ and ‘partnership’ relationships. Nevertheless there are some traits about communication between PHCTs and POONSs which are indistinct, contributing to a mixed ‘partnership/empowerment’ relationship. These communication similarities are prompted by the planned referrals at the onset of terminal care.

A child’s terminal illness is a focal point in the development of professional relationships between GPs, DNs and regional POONSs². General practitioners working within both regional catchment areas felt that meeting POONSs at an early stage opened continuing channels of communication between themselves and POONSs; some of these relationships continued through a family’s bereavement. Most GPs acknowledged that communication was a two way process. However in a ‘partnership/empowerment’ relationship they seldom needed to contact POONSs since POONSs themselves frequently pre-empted contact. This enabled GPs and POONSs to work well together during a child’s terminal illness.

A second feature of communication between POONSs and PHCTs which contributed to a mixed ‘partnership/empowerment’ relationship concerns face-to-face contact between POONSs and DNs. Having face-to-face contact with POONSs was of paramount importance in forging two-way communication between POONSs and DNs, regardless of whether ‘partnership’ or ‘empowerment’ relationships developed. This was illustrated by one DN who had periodically visited a child since diagnosis:

² The HV’s role appears ill defined during terminal care. The reason for this appears to lie in the more proactive and specialised psychosocial support required during this period. A HV from the pilot study who had a long, well established relationship with the family of a child who died said:

I’m sure that (the mother’s) perception of me was as a health visitor which I was, and had nothing to do with sick children, I was there for the sore bottoms and the feeding and the crying and the sleepless nights and the wind and the what have you and this illness was a thing apart

(HV1, Moorcroft Children’s)
until the time she met the MPN with whom she was working, her contact was restricted:

*I think it probably was actually, not having met her before it was quite difficult to ring up and say, 'look I don’t think I’m coping with this very well’*  
(DN3 Northern City area)

And another, who prior to meeting a POONS, had been anxious about providing care to a dying child and her family:

*POONS I] came home with (the patient) and we met up again in the house and I took a colleague with me….. [POONS I] left us phone numbers, her contact number and if she wasn’t there then her colleague had all our numbers and it was done very well*  
(DN11, Southern Regional area)

Reiterating, planning meetings at the outset of a child’s terminal care opens up channels of communication between POONSs and PHCTs. For DNs in particular these are reinforced by continued face-to-face contact. These components of communication are common to both ‘partnership’ and ‘empowerment’ thereby contributing to the notion of a mixed ‘partnership/empowerment’ typology.

**Decision Making in ‘Partnership/Empowerment’ Relationships**

Although attaining decision-making abilities is largely attributed to an ‘empowerment’ relationship through the skilling of DNs during terminal care, there is also a ‘grey’ area in which decision-making is neither confined to one type of relationship nor another. Alluded to earlier, HVs have often had relationships with families prior to the onset of a child’s disease; providing primary care during treatment remains their domain. In ‘partnership/empowerment’ HVs may retain decision-making responsibilities in accordance with their prior relationships with families:
[POONS 1] thought it was a good idea (to visit family in hospital) but we didn’t know, they weren’t expecting Jacob to stay in so long…. [POONS 1] didn’t mind either way but we kind of talked about it and she was saying you know mum had seen a lot of people but you know kind of me to just come and say hello so that she’ll get the impression that I would have known what had gone on in hospital

(HV10, Southern Regional area)

They may also develop new decision-making skills which enable them to take on new responsibilities such as providing psychosocial support and advice to families. This was depicted by a HV in the Northern City area who said:

(without contact with MPN 1) I’d have been very wary about going into the home and saying, ‘I think you ought to go, isn’t it time you took the child back to ‘….. enabling me to go and give the support to the mother and to offer more support

(HV4, Northern City area)

Providing Access to DN

DNs, unlike HVs and GPs do not usually develop relationships with children with cancer or their families prior to a child’s diagnosis. In both ‘partnership’ and ‘empowerment’ relationships they rely heavily on POONSs for access since POONSs often co-ordinate a child’s community care. A feature of ‘partnership/empowerment’ therefore concerns the access gained by DN through POONSs. For DN whose access to patients is facilitated by POONSs (often initiated through the case conference) their anxieties may be reduced, they develop good rapport with POONSs and their relationships with families are eased. These points are best illustrated below:

[MPN 1] phoned and she said, ‘I think they might appreciate it if you went in’, I didn’t want to go, I was so nervous, but the mum wasn’t there, the dad was and I didn’t have much dealing with him, but then he really did appreciate me going… they were so nice about it

(DN2, Northern City area)

I think if [POONS 1] hadn’t been there to keep saying, ‘well I’ll bring the district nurse with me again this time’ it would have been a case of like, we would have only got in when things were really bad, probably you know days before she died, which would have been really awful, wouldn’t it?  

(DN10, Southern Regional area)
In summary, there are features of both 'partnership' and 'empowerment' which lead to 'grey areas' between the two types of relationships. These include providing access to DNs, enabling HVs to maintain or gain decision-making powers, allowing opportunities for face-to-face contact, planning terminal care and opening channels for two-way communication. These grey areas have led to the existence of a mixed 'partnership/empowerment' relationship which is affiliated with POONSs working at regional centres. This type of relationship enables community nurses to work closely with POONSs, feel both professionally and emotionally supported, and feel contented with their own efforts.

A 'Disempowerment' Relationship

If the notion of 'empowerment' is implicit through a 'hands-off' approach to nursing, then it follows that 'disempowerment' may be a consequence of a 'hands-on' type of care. This study has demonstrated that POONSs identified with the CLIC model adopt a 'hands-on' approach to nursing care; the data suggest that CLIC nurses are most closely identified with 'disempowerment'. Since it is CLIC's philosophy for 'their' nurses to follow patients and their families through a child's disease, providing total 'direct' care (Bignold et al. 1994a), it is perhaps not surprising that POONSs associated with the CLIC model were most closely identified with this relationship type. There are several characteristics from both stages of this research which identify CLIC nurses with 'disempowerment'. These are outlined in the discussion below and are highlighted in Table 11.1.

Unplanned Referrals

In as much as planning a child's terminal care prior to discharge from hospital features in both 'empowerment' and 'partnership' relationships, a feature of 'disempowerment' concerns a lack of forward planning and involvement of PHCTs both during terminal care and at the outset of a child's 'cancer journey'.

An example of this is demonstrated by GPs working in the Westlands area whose contact with POONSs at the outset of a child's disease was 'hit and miss'. Some GPs said they had not been contacted at all by the CLIC nurse whilst others reported
several discussions. Whilst it could be argued that different diseases and thus different treatment protocols\(^3\) might allow for these discrepancies, the same would have to be said in all centres. Such ‘hit and miss’ approaches would therefore always be apparent. This is not the case and has already been demonstrated in ‘partnership’ where relationships are forged between POONSs and GPs at the outset of a child’s cancer journey. This occurs irrespective of disease and treatment. In addition a ‘hit and miss’ approach to contact with GPs at this time is indicative of the ‘minimal’ communication patterns between all CLIC nurses and PHCTs (Tables 11.2, 11.3, 11.4).

A second example of unplanned referrals which link the CLIC approach to ‘disempowerment’ includes contact with GPs at the onset of a child’s terminal care. The case conference approach to planning terminal care, so apparent in ‘partnership/empowerment’ is absent in this type of relationship. No GPs in the Westlands area had been contacted at the outset of a child’s terminal care and any contact between themselves and POONSs was often more by chance than planned. For example GPs commented that they only: ‘met.. a couple of times by accident because she happened to be in the house’ (GP7, Westlands District area) or ‘didn’t meet the nurse, if there was a nurse involved, was there?’ (GP6, Westlands District area). Exceptionally one GP had had some communication with the CLIC nurse early in a child’s terminal care. However he concluded that this was the result of previous acquaintances with the local children’s ward (where she had previously been the ward sister) and knowledge of the availability of the CLIC nursing service rather than any preplanning by the nurse.

\(^3\) Treatment protocols vary enormously, depending on the type of malignancy a child is diagnosed with. Whilst some children will receive all treatment as an outpatient, others will require short periods of time in hospital. Others still will be admitted for the initial diagnosis and remain in hospital for many weeks or months for intensive chemotherapy.
In a 'disempowerment' relationship referrals to DNs are similarly unplanned. Indeed ‘access’ to patients is denied by POONSs and is provided by other ‘gatekeepers’ - few DNs in the Westlands area were involved in a child’s terminal care (see Tables 7.1 & 8.1) and those who were had not been notified by the local POONS service. This would suggest that the CLIC nurse plans to provide ‘hands-on’ nursing herself rather than hand over care as in ‘empowerment’ or share it in ‘partnership’. One district nurse in the Westlands area for example, was already visiting another member of the family when a child became terminally ill; a second gained access through her close working relationship with a GP, whilst a third (unaware of the CLIC nurse’s involvement) was requested by the ITU, to care for an adolescent patient with a Hickman line. Although it has been recognised that adolescent patients have special needs (e.g. Burr 1993, Russell-Johnson et al. 1993, Farrelly 1994, Conway et al. 1996) often falling between adult and paediatric nursing services, this patient’s care had previously been provided through the paediatric unit. The referral was late in the patient’s care, and like others, was unplanned and un-coordinated:

in my view I met him too late because at this stage he was receiving treatment through a central venous line... considering we had an awful lot of nursing care to give at the end it would’ve been nice to have been involved at an early stage so that they could’ve got to know

(DN7, Westlands District area)

Communication in a ‘Disempowerment’ Relationship

It has earlier been contended that communication between POONSs and PHCT plays a major role in distinguishing between ‘partnership’, ‘empowerment’ and ‘disempowerment’. A feature of ‘disempowerment’ lies in communication between POONSs and PHCTs: POONSs associated with the CLIC model suggested ‘minimal’ levels of contact through the ’phone calls and visits they made (Tables 11.3 & 11.4). In particular they made fewer visits to DNs to establish professional relationships with them (Table 11.2 (a)). Whilst it might be assumed that smaller caseloads are responsible for fewer visits and ’phone calls, the PHCT data set does not substantiate this. General practitioners and DNs in the Westlands locality in particular, reflected on the lack of communication with the CLIC nurse with whom they worked.
When terminal care is unplanned and initial contact between POONSs and PHCTs is erratic, continuing communication remains poor. Whilst some GPs considered their lack of contact with the CLIC nurse, and consequent exclusion from care, to be in the best interest of families, others reflected on the detrimental long-term implications this had had on their professional relationships both with the families concerned and on occasions, with their colleagues. Two GPs in particular considered their lack of contact with the CLIC nurse resulted in families withdrawing from the practice following the death of the child.

The importance of face-to-face contact with POONSs in the development of a mixed ‘partnership/empowerment’ relationship has earlier been established. Therefore it is argued that when face-to-face contact is not established, poorer communication develops with POONSs resulting in ‘disempowerment’. In particular, less face-to-face contact was established between CLIC nurses and DNs due to the fewer visits that were made to them (Table 11.4 (a)). This is substantiated through the case study data since only one DN in the Westlands area met the POONS there. Even she suggested:

*maybe we could have had a stron- more face-to-face contact or felt that the liaison was a little easier perhaps*

(DN8, Westlands District area)

Not only did a lack of planning, reduced levels of contact and a lack of face-to-face contact impede the development of professional relationships in a ‘disempowerment’ relationship but attempts at two-way communication were also hampered by the difficulty some community staff had in making contact with the CLIC nurse at Westlands. Again the DN referred the adolescent patient from the ITU commented:

...it was also very difficult to get hold of [district POONS] ‘cause she wasn’t down here everyday and it was difficult to track her down to contact her... so the arrangement was a message left up on the children’s ward and it didn’t always work out that we contacted one another.... she told me if there was a change in treatment that was it really

(DN7, Westlands District area)
The consequence of diminished communication between POONSs and PHCTs is that poor working relationships ensue. Although poor communication between CLIC nurses and GPs is apparent both at the outset of a child's disease and during terminal care, it is particularly explicit through the poor relationships developed between POONSs and DNs.

**Lacking 'Specialist' Skills**

Embraced in 'empowerment' is the acquisition of 'specialist' skills. In 'disempowerment', PHCTs, and GPs in particular, lack the powers to take an active role in terminal care because they have not been taught the appropriate skills to do so. This is illustrated by POONSs visiting GPs to advise on aspects of terminal care. In this example CLIC nurses made the least number of visits for this purpose (Table 11.2 (c)). Corroborating the association of the CLIC approach with not teaching GPs these skills, GPs in the Westlands vicinity said they were informed about changes in a child's condition but were seldom invited to discuss their own input. One GP did consider that he had excellent: *communication with the CLIC nurse (but) felt uncovered at the end* (GP5). This was because he had received information about changes in a child's condition but lacked the skills and knowledge required to preplan and provide the care demanded of him. This was exacerbated by poor communication and difficulty in obtaining the nurse which has been discussed above.

**Displacing PHCTs**

In a 'disempowerment' relationship displacement of health care professionals sometimes occurs. Although there is some evidence from the PHCT data set to suggest that GPs may be displaced by POONSs through their minimal involvement during a child's terminal illness, displacement of HVs' roles is more commonly apparent. HVs from the Westlands area had diverse opinions of their relationships with 'their' CLIC nurse. Nevertheless a sense of 'disempowerment' prevails when HVs are prevented from fulfilling their roles. This is marked by a feeling that contact with POONSs is limited and primarily occurs during 'crisis intervention'. These points are best summed up thus:
I would've been, perhaps been, a more regular visitor if [district POONS] hadn't been involved, so that would've put more onus on me as a support worker

(HV8, Westlands District area)

I think in some ways maybe I was only contacted because of the, the difficulties in getting this diagnosed and there was a little bit of ill feeling between, I think, the relationships between some of the professionals and I think this is why I was brought in, not to pour oil on troubled waters but there was obviously a lot of unhappiness there

(HV9, Westlands District area)

Intruding Upon Established Relationships

An additional feature of 'disempowerment' concerns intruding upon intimate relationships developed between POONSs and families in their care. Many of those interviewed during the course of the qualitative phase of this research (both hospital and community-based) talked of the particularly close relationships which develop between POONSs and families. These close relationships, it was felt, arise through POONSs' abilities to 'boundary hop' between the hospital and the community and have previously been discussed in Chapters Eight, Nine & Ten. However this feature contributes to 'disempowerment' when PHCTs feel they are 'intruding' on these close knit relationships. This most commonly occurs when DNs are not directly provided with access to patients by POONSs and their roles are consequently uncertain. These features have earlier been equated with the Westlands area. However some HVs in the same area also considered they were intruding upon established relationships between families and POONSs inspite of, in some instances, themselves having previously long histories with families. This 'intrusion' upon established relationships is best illustrated by a DN and a HV who respectively commented:

I didn't want to rock the boat because he'd been [district POONS's] patient longer than mine but to me that's what made a lot of problems

(DN7, Westlands District area)

in actual fact you find sometimes when a family has a very close bond with a particular professional you almost feel that you're intruding in on that, and I think it's very important to realise when not to intrude on this relationship

(HV9, Westlands District area)
Effects of ‘Disempowerment’ for PHCTs

Since less is learnt by PHCTs about the disease processes and management of childhood malignancy in ‘disempowerment’, an air of mysticism about childhood cancer remains. Therefore, it should be pointed out that although poorer professional relationships develop between POONSs and PHCTs, PHCTs in this study acknowledged that the ‘disempowering’ approach adopted in the Westlands area was in the best interests of children and their families, since they were cared for by ‘specialists’ (see Chapter Ten).

In spite of suggesting that the ‘disempowering’ nature of the CLIC nursing service is in the best interests of families, PHCTs, and community nurses in particular, do not feel professionally fulfilled by this type of relationship: community nurses from the Westlands area were left questioning their role. Both job satisfaction and clear role identification contributed to the processes of both ‘partnership’ and ‘empowerment’. Where both were lacking the process of ‘disempowerment’ was further contributed to. This is epitomised by one DN who said:

neither of us, I didn't know who was in control of the patient’s care because she was involved....... so I didn't really know who was in control of the situation... in the end I took control of the situation when he became bedridden and wasn’t able to go to the hospital...... so we were two separate bodies giving what we thought was the right care but nothing was co-ordinated

(DN7, Westlands District area)

Conclusion

This chapter has discussed the relationship typology which exists between POONSs and PHCTs. Whilst it has recognised that individuals will develop their own working styles it has suggested that three distinct types of relationship exist: ‘empowerment’, ‘partnership’ and ‘disempowerment’. These relationship types it is contended, have strong associations with the three ‘Funder’ models described in Chapter Six. It has been argued that both ‘empowerment’ and ‘disempowerment’ relationships have developed as a direct influence of the strategies adopted by the charities with which both MPNs and CLIC nurses are associated. ‘Partnership’ relationships have some distinct characteristics of their own including developing relationships with PHCTs
at an early stage in a child's disease trajectory. However it is suggested that there are also some traits of 'partnership' which are indistinct from those in 'empowerment' relationships. Compared with both 'empowerment' and 'disempowerment' (which are influenced by the charities with which they are associated), it is difficult to determine the elements which contribute to 'partnership'. However, the lack of distinction between 'partnership' and 'empowerment' which contribute towards a mixed 'partnership/empowerment' may be accredited to the regional location of these POONSS.

It is only possible to surmise why distinctions in the types of relationships exist between regionally-based POONSS (affiliated to both the 'Mixed Funders' and the Macmillan models). Although it is probable that CRMFs' strategies result in empowerment, this does not explain why other regionally-based POONSS incline towards 'partnership' rather than 'empowerment'. One explanation would be to suggest that health care professionals, rather than charities, influence the relationships between POONSS and PHCTs in the 'Mixed Funders' group. Another which would fit with the greater tendency for POONSS affiliated with the 'Mixed Funders' model of POONSS to practice a more mixed hands-on and hands-off approach, would be there greater experience in paediatric oncology nursing prior to becoming POONSS. It is possible that POONSS with greater experience of working with families at the outset of a child's disease have a greater understanding of the impact of the diagnosis of childhood malignancy on families than those with less experience. This being so they may have a greater understanding of the importance of working with PHCTs during this period. Another explanation for 'partnership' related to this greater level of clinical work experience is that POONSS in this group may have greater difficulty 'letting go' of clinical skills which they have spent a long time developing.
Chapter Twelve - Professional Relationships between POONSs and Hospital-based Professionals

Introduction
The previous chapter suggested that POONSs work closely with different professional groups across two settings: the community and the acute hospital environment. It argued that the strategies adopted by the two main charities associated with funding POONSs created a typology of the nature of relationships between POONSs and PHCTs. The influences of alternative funding sources of POONSs upon professional relationships between POONSs and other healthcare professionals are further analyzed in this chapter.

This chapter examines relationships between POONSs and hospital-based health care professionals at both senior and junior levels including: consultants, junior doctors, sisters (Sr.) and junior SNs. Whilst the data suggest that professional relationships are influenced by individuals' personalities, lengths of service, specialist areas of interest and previous exposure to personality conflicts, the chapter suggests first that POONSs have very different relationships with senior medical and nursing staff compared to those with junior hospital staff. Second that relationships between POONSs and hospital-based health care professionals are influenced by the strategies of the different charities associated with POONSs. The greatest differences in working relationships between POONSs and hospital-based health care professionals occurs between POONSs at regional centres (associated with both the Macmillan and ‘Mixed Funders’ models) and those at DGHs, affiliated with the CLIC model.

Whilst some treatment and the majority of terminal care is provided in the community and is shared, albeit to different degrees, between PHCTs and POONSs, children receiving chemotherapy will have the majority of their care in hospital, either as in-patients, as out-patients or a combination of both. Treatment and its monitoring may be provided by the regional centre or a child’s DGH and elements of care are shared between hospital-based health care professionals and POONSs. During periods when children require hospitalisation, responsibility for their care is assumed by the hospital
which means that ‘partnerships’ between health care professionals in the hospital setting are inherently present. This chapter constructs a ‘partnership’ typology between hospital-based health care professionals and POONSs. Analysis of data from both stages of the study suggests that the geographical location of POONSs (although itself affected by the strategies of charities associated with funding their posts) is the primary influence on the ways in which ‘partnerships’ evolve. It will highlight four different ‘partnerships’ which, in addition to POONS work location, are determined by patient ‘ownership’ and the balance between nurse-led and doctor-led care.

Firstly, where POONSs provide a ‘hands-on’ type of care, hospital-based nurses and junior doctors provide treatment and care to children with malignant disease only in the absence of the POONS, when care is relinquished to them. Instead, most of their time is occupied caring for and treating children with a variety of other conditions, the ‘ownership’ of children with malignant disease lying predominantly with the POONS. This type of ‘partnership’ is referred to as ‘Relinquishment’ and exists only between the POONS and junior medical staff and nurses at Westlands District Hospital. It is therefore an example of partnerships developed between hospital workers and district-based, CLIC-funded POONSs.

A second type of partnership which exists where POONSs provide ‘hands-on’ care reveals a power relationship between POONSs and senior medical staff. Here, consultants retain responsibility and ‘ownership’ of patients and are primary decision-makers (particularly regarding symptom management during terminal care). This ‘partnership’ type is one in which the consultant not only monitors a patient’s condition but also oversees the work of POONSs; this type of partnership is referred to as ‘Hierarchical Ascendency’. ‘Hierarchical Ascendency’ exists when POONSs are perceived to possess specialist nursing skills and in-depth information about families’ dynamics, yet are seen to lack the ‘medical’ knowledge required to make treatment-related decisions. Here, terminal care is doctor-led. This type of ‘partnership’ is only identified between the POONS and the consultants at Westlands District Hospital and is an example of relationships developed between district-based, CLIC-funded POONSs and senior medical staff.
Thirdly, an ‘Integrated Reciprocity’ partnership is defined in which care and ‘ownership’ of patients is shared between regionally-based POONSs and other health care professionals at tertiary centres, at different stages of a child’s illness trajectory, where each is mindful of the others’ roles. This type of partnership, the data suggests, most commonly occurs between POONSs at regional centres and senior colleagues, irrespective of the ‘Funder’ model with which they are associated. Lastly, an ‘Independent Reciprocity’ partnership is developed where POONSs and other health care professionals at tertiary centres share ‘ownership’ of patients, but are sometimes oblivious of each others’ functions. This more frequently occurs between POONSs and junior staff, regardless of ‘Funder’ model. There are characteristics common to both ‘Reciprocity’ partnership types which are also discussed. Characteristics of the ‘partnership’ typology are summarised in Table 12.1 whilst the distinctions between ‘Integrated Reciprocity’ and ‘Independent Reciprocity’ are summarised in Table 12.2.

‘Relinquishment’
This section of the chapter discusses the first of four types of ‘partnership’ which exist between POONSs and hospital-based health care professionals. More particularly it explores how ‘hands-on’ nursing care, associated with the philosophies of CLIC and depicted through POONSs associated with the CLIC ‘Funder’ model, affect the type of partnership which develops between POONSs, nursing colleagues and junior medical staff. Drawing particularly on data from the Westlands District Hospital case study, it provides an example of the first of two types of partnership which exist in this ‘hands-on’ environment: it has been termed ‘Relinquishment’. Features of ‘Relinquishment’ have been summarised in Table 12.1.
Table 12.1 Features of a ‘Partnership’ Typology between hospital-based health care professionals and POONSs

Relinquishment:
- Distanced relationship between POONSs and SNs
- SNs, SHOs and Srs. hindered from providing care due to ward based nature of POONS’s work
- Increased stress to SNs when involved in patient care
- ‘Ownership’ of patient care predominantly with POONS
- Potentially renders other professionals roles as unnecessary

Hierarchical Ascendency:
- Consultants maintain overall responsibility of patients
- POONS lacks professional autonomy (consultant controls work)
- Terminal care is ‘doctor-led’

Reciprocity:
- Joint management/shared ‘ownership of patients
- Frequently FU care initiated by others
- SNs possess greater understanding of community work
- SNs in training accompany POONSs on visits
- Consultants procure funds for POONS services
- Terminal care is ‘nurse-led’
Table 12.2 Summary of distinctions between ‘Integrated’ and ‘Independent’

Reciprocity Partnerships

**Integrated Reciprocity:**

- Possesses advisory role (palliative care) to all junior staff
- Utilisation of Primary Nursing
- Negotiated areas of work between POONSs and junior staff
- Work of POONSs integral and complementary to others
- Share teaching commitments, decision-making powers and status (Srs.)
- Share information giving with others
- Induction programs given to SHOs by POONSs

**Independent Reciprocity:**

- Limited contact between POONSs and others
- Information giving of little benefit (SHOs)
- Professionals work independently of others
- Potential for repetition of work by others
- POONSs ‘own’ terminal care
'Ownership' of Children with Malignant Disease

POONSs associated with the CLIC model provide nursing care to in-patients as well as children at home (see Chapter Six). They are also seen to possess greater 'specialist' knowledge of childhood malignancy than their more 'generalist' nursing colleagues (see Chapter Ten). Consequently, the most distinguishing feature of 'Relinquishment', which arises from POONSs providing 'hands-on' care and possessing greater expertise, is that they are seen to take responsibility for children with cancer and their families, thus 'owning' them; in particular, they 'own' hands-on care. This means that other staff on the paediatric unit, especially junior SNs, rarely care for these children and their families. Exceptionally, junior medical staff may feel that they assume greater 'ownership' of patients than their nursing colleagues. As one trainee GP at Westlands considered:

(they are) [district POONS's] patients from a nursing point of view rather than a medical point of view. They become my patients as well when they come on the ward 'cause I assume their medical responsibility for them or a small part, thankfully, of their medical responsibility

(SHO2, Westlands District Hospital)

However, this SHO did go on to say that tasks, such as taking blood samples, were delegated to him by the POONS, since she had greater insight into patient requirements than he. 'Ownership' of tasks by POONSs, is also supported by consultants at Westlands who suggested that in-patient care is predominantly the domain of POONSs. An example of this is given by one consultant who suggested that chemotherapy administration (often the responsibility of SHOs in DGHs) was only given to patients when 'relinquished' to SHOs, by the POONS, in her absence. Hence 'ownership' remains with POONSs unless absent from the ward. As one consultant said:

[District POONS]... I mean she does Vincristines and things like that, sometimes it's our junior staff

(Consultant 3, Westlands District Hospital)
CLIC nurses cannot be ever present on the ward since there are periods when they may be off duty or visiting children in the community. At these times ‘ownership’ of in-patients is temporarily ‘relinquished’ to other members of staff, who more commonly nurse/treat children with a variety of other conditions. This has been intimated by the consultant quoted above. Temporarily relinquishing ‘ownership’ of patients however, is best illustrated by the sister at Westlands who explained:

she may start the chemo... and it was important that [district POONSs], you know should, you know sort of work with us and that she wasn’t going to be there all the time when these children were having all their chemo

(Sr2, Westlands District Hospital)

Passing patient ‘ownership’ over to others for a certain span of duty may be responsible for developing teamwork particularly amongst senior staff who work more closely with POONSs than junior personnel: ‘I mean we’ve worked quite closely together when we do have children that are in you know’ (Sr2, Westlands District Hospital). Furthermore, ‘ownership’ of patients by CLIC nurses is perceived to advantage families of children with malignant disease since it provides continuity of care. More particularly it eases the work loads of other nursing staff. As one SN embarking on RSCN training confessed:

I mean she does take a load, quite a bit off our workload really because if we’ve got, you know, an oncology patient down at the far end of the ward and we’ve got the ward that’s full, it takes one member of staff out of our staff quota, which isn’t good most of the time

(SN7, Westlands District Hospital)

In spite of these perceived advantages, there are disadvantages of ‘Relinquishment’ both for staff and families, when patients and their care are owned by POONSs. These problems arise particularly for junior nursing staff and are discussed below.
Distancing Staff from Patients and POONSs

One of the disadvantages of POONSs taking 'ownership' of patients is that other staff are distanced from both POONSs and patients. Distancing between POONSs and other health care professionals occurs since limited necessity for contact arises when POONSs 'own' patient care. Secondly, distancing exists because contact between other hospital staff and families is reduced to times when 'ownership' has been temporarily 'relinquished' to them. The first point is illustrated by POONSs associated with the CLIC model who suggested distanced relationships with ward nursing colleagues compared to all other POONSs (Table 12.3). This point, along with the second (creating distance between staff and families), is demonstrated by junior staff, and by SNs in particular, working at Westlands District Hospital. Here, where the CLIC nurse provides the majority of care, junior staff have limited opportunity to work with her and to have contact with patients. The SN undertaking RSCN training remarked:

*being an SEN and being an RGN, not having any contact with the oncology... you know, you just sort of - we're basically the outsider, just looked in*

(SN7, Westlands District Hospital)

In a 'Relinquishment' partnership, limited contact is exacerbated when SNs have previously worked permanent night duty. This is depicted by one SN who said:

*we were on permanent nights, yeah, originally, so you know, we didn't know that there was [district POONS] available for contact, we knew of her name, but I must admit for about three years I couldn't have put a face to her name*

(SN9, Westlands District Hospital)

Creating Anxiety

If CLIC nurses provided 24 hour in-patient care, then distancing themselves from other staff and other staff from patients may not be problematic, since they could theoretically segregate themselves completely from the rest of the unit. But with one POONS at most centres where CLIC and other district-based services operate (see Chapter Six), this is unrealistic. Hence patient care must be relinquished to others when single-handed POONSs are unavailable to provide the nursing care required
Table 12.3 Percentage of POONSs without a close working relationship with nurses, comparing 'Funder' models

<table>
<thead>
<tr>
<th>RELATIONSHIPS WITH NURSES¹</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Macmillan</td>
<td>CLIC</td>
</tr>
<tr>
<td>Those WITHOUT close</td>
<td>2 (40%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Those WITH close</td>
<td>3 (60%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>5 (100%)</td>
<td>10 (100%)</td>
</tr>
</tbody>
</table>

* See List of Abbreviations

¹ Includes nurses from wards, OPDs, other CNSs and some community nurses since: 'she can't be here all the time' (SHO2, Westlands District Hospital). Seldom taking ownership of patients, and frequently being distanced from POONSs and children with cancer disadvantages junior staff, since when they are required to provide nursing care to these families, undue stresses are put upon them. This point has previously been discussed in relation to conferring 'specialist' status on POONSs in Chapter Nine. The presence of a CLIC nurse means that junior SNs are generally spared from nursing children with cancer. Being removed from these children and their families ensures that they do not have to worry about providing specialist nursing skills or cope with the anxieties which are inherent when nursing children with life-threatening diseases. However, a consequence of frequently being removed from this situation is that SNs' anxieties become heightened when required to nurse children with cancer. This is epitomised by one SN who said:

"when [district POONS's] not there you've gotta step in, that's what I worry about, that... (district POONS) does everything and then when she goes off duty whatever time, 5-ish, then we take over, the RSCN takes over"

(SN8, Westlands District Hospital)
Negating Other Professionals

When the majority of hands-on care is provided by POONSs and relinquished to others only when absent from the ward, other members of staff may be deemed superfluous to the needs of children with malignant disease and their families. The roles of other health care professionals are negated except when care is temporarily relinquished to them in the absence of the POONS. This differs greatly to 'Reciprocity' partnerships, discussed later in the chapter, where POONSs' roles are perceived to be integral to the work provided by others. An example of negating other professionals' roles is highlighted by an SHO who not only contemplated his own lack of professional identity brought about by the presence of the CLIC nurse at Westlands, but also considered:

whether we'd need to have the, our consultants as well as the [regional centre] consultants, as well as [district POONS] and whether it wouldn't be better if [district POONS] and the [regional centre] consultants sort of worked together

(SHO 2, Westlands District Hospital)

In summary, a 'Relinquishment' partnership exists when POONSs retain hands-on care in hospital as well as the community. This means that they are seen to 'own' children with cancer and their care; 'nursing' and 'medical' tasks are only relinquished to others in her absence. At Westlands, only nurses who hold RSCN qualifications nurse children with malignant disease. This means that senior nursing staff work more closely with POONSs than junior SNs. Even then care for such children is only relinquished in the absence of the POONS. Consequently, junior medical and nursing staff are distanced both from POONSs and from patients, which creates stresses particularly for junior nurses, when required to provide care to children with malignant disease. This contributes to a somewhat distanced relationship between the POONS and SNs and potentially renders unnecessary other health care professionals.
'Hierarchical Ascendency'

'Hierarchical Ascendency' exists in the same environment as 'Relinquishment' where hands-on nursing care is provided by POONSs, to children in hospital. These practices have earlier been linked to the CLIC model of POONSs and this type of partnership is consequently linked with CLICs' strategies. Here, although junior doctors and nursing staff perceive POONSs to be the 'owners' of patients, POONSs do not make 'medical' decisions; overall responsibility for and 'ownership' of patients is retained by consultants. The work of POONSs is governed by consultants and terminal care is co-ordinated by them. Each of these characteristics in turn mean that POONSs in this type of partnership have limited professional autonomy. These factors and other traits of 'Hierarchical Ascendency' are the focus of this section of the chapter and are summarised in Table 12.1.

Requiring Medical Support

It has earlier been contended that POONSs located at DGHs (and hence predominantly associated with CLIC), lack the depth of knowledge about paediatric oncology which other regionally-located POONSs possess (see Chapter Ten). Associated with this, is a tendency for POONSs to lack the authority to make medical decisions about patients, depending on medical staff to make decisions on their behalf. Given that DGHs often lack middle grade medical staff, it is inevitable that district-based POONSs rely on consultants for their medical support. This brings about close working relationships between consultants and POONSs. One of the features of 'Hierarchical Ascendency' is that POONSs require supervision and support from consultants. The POONS data set suggests that, in addition to POONSs associated with CLIC, those at DGHs have closer relationships with senior medical staff than other POONSs (Table 12.4). More common however amongst CLIC-funded POONSs than others at DGHs, they also rely most on doctors for professional support (Table 12.5). This may be accredited to the presence of CLIC-funded Associate Specialists. Requiring medical support in a 'Hierarchical Ascendency' partnership is also born out by the consultants at Westlands District Hospital. Here, consultants demonstrate governing the work of the CLIC nurse through the guidance provided to her. This is best illustrated by the consultant who commented:
Table 12.4 Professional relationships between POONSs and doctors, comparing ‘Funder’ models of POONSs

<table>
<thead>
<tr>
<th>RELATIONSHIPS WITH CONSULTANTS</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mac* (N=5)</td>
<td>CLIC (N=10)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>District (N=3)</td>
</tr>
<tr>
<td>Only work closely with consultants&lt;sup&gt;1&lt;/sup&gt;</td>
<td>2(40%)</td>
<td>7(70%)</td>
</tr>
<tr>
<td>Work closely with other doctors&lt;sup&gt;2&lt;/sup&gt;</td>
<td>2(40%)</td>
<td>3(30%)</td>
</tr>
<tr>
<td>Don’t work closely with any doctors</td>
<td>1(20%)</td>
<td>-</td>
</tr>
</tbody>
</table>

<sup>1</sup> Includes Senior Registrars, Associate Specialists etc.

<sup>2</sup> Includes all hospital doctors and GPs

Table 12.5 Professional support obtained from senior doctors, comparing ‘Funder’ models of POONSs

<table>
<thead>
<tr>
<th>SUPPORT FROM DOCTORS</th>
<th>FUNDER MODEL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mac* (N=5)</td>
<td>CLIC (N=10)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>District (N=3)</td>
</tr>
<tr>
<td>Gain support from doctors</td>
<td>2(40%)</td>
<td>6(60%)</td>
</tr>
<tr>
<td>Don’t gain support from doctors</td>
<td>3(60%)</td>
<td>4(40%)</td>
</tr>
</tbody>
</table>

* See List of Abbreviations

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I mean if it is a minor infection or something and we will decide whether a blood test perhaps at home might help. Ultimately it's my decision but we will discuss it and we will decide whether she will go and visit and do a blood test.

(Consultant 3, Westlands District Hospital)

Learning 'Specialist' Nursing Skills
An additional characteristic of 'Hierarchical Ascendency' lay in the 'nursing' skills of POONSs. Consultants at Westlands acknowledged that the POONS's length of service (which was greater than their own) affected the degree to which they were able to learn 'nursing' skills from her. Where in-depth knowledge of childhood malignancy is lacking, a feature of the 'skills' in 'Hierarchical Ascendency' lies in a POONS's close relationships developed with families, over time. The small caseloads of POONSs working at DGHs allow for their availability and accessibility. This enables POONSs, such as the one at Westlands, to maintain up-to-date information regarding a patient's condition - a trait that is perceived to contribute to the 'specialist' skills of POONSs (See Chapter Ten). This 'specialist' nursing knowledge, is felt to be important for consultants:

often you see spotting something early can be very important, so often she will say, 'I'm just off to see so-and-so, mum rang half an hour ago to say that her temperature was just up', so you know the 'phone call came back, 'her temperature is up, I think she should come in', you're waiting for it, you're ready for it

(Consultant 2, Westlands District Hospital)

Not only are consultants able to learn about family histories from POONSs in this type of partnership, but learning specialist practical 'nursing' skills, such as Hickman line care, is also an attribute. This is a feature unique to consultants at Westlands, since none of those at regional centres highlighted practical 'nursing' tasks as a feature of their work. It is probable that the necessity of consultants at Westlands to learn 'nursing' procedures reflects the lack of middle grade medical staff and the greater patient contact that consultants at DGHs generally have, compared to those at tertiary centres.
Neither of the two senior doctors at Westlands contemplated that 'their' POONS possessed specialist knowledge, besides the ‘nursing’ skills, from which they learnt. In this type of partnership decision-making about patient management is undertaken jointly, but responsibilities for making decisions remains the domain of the consultant rather than the POONS. This reflects the lesser knowledge-base of all CLIC nurses, compared to other, regionally-based POONSs. Developing close relationships with and knowledge about family dynamics assists consultants to make patient management decisions.

‘Medically-led’ Terminal Care
Another feature of ‘Hierarchical Ascendancy’ concerns the role of consultants in coordinating terminal care. Although the flexible nature of POONSs’ work enables them to more regularly visit children at home, in this type of partnership visiting terminally ill children at home is the province of both consultants and POONSs. Who becomes the primary carer for individual families depends, in the main, on personal preferences both of families and health care professionals. Since consultants learn ‘specialist’ nursing tasks from POONSs in ‘Hierarchical Ascendancy’ it may be assumed that any ‘specialist’ tasks required at such visits may be conducted by either the POONS or the consultant. As both consultants at Westlands suggested:

.....a little bit of everything, I mean there have been only three of us... nobody's too proud if you see what I mean, the roles are not sort of that fixed... it's everyone has to sort of muck in together
(Consultant 2, Westlands District Hospital)

...with terminal care, liaising with family doctors... she is probably the person... but I do too and so does [name], our associate specialist
(Consultant 3, Westlands District Hospital)

In spite of ‘mucking in together’, in ‘Hierarchical Ascendancy’ overall responsibility for managing terminal care and ‘ownership’ of terminally ill children is retained by consultants. It is they who make the medical decisions whilst the POONS is: ‘much more involved in practical procedures’ (Consultant 2, Westlands District Hospital) and in providing hands-on care. Thus terminal care is medically-led.

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**Limited Professional Autonomy**

Where ‘ownership’ of patients is retained by consultants, terminal care is led by them and in-depth knowledge of POONSs is lacking, the work of POONSs is, in part, monitored by consultants. Recent studies have suggested that nurses in general hospital settings maintain an acceptance of authority from consultants (Mackay 1993, Walby et al. 1994). In this study the notion of consultants maintaining authority is born out in ‘Hierarchical Ascendency’, in particular through the controlling by consultants, of POONSs’ work. This restricts the professional autonomy of POONSs and limited professional autonomy is a major feature of this type of partnership.

In summary, ‘Hierarchical Ascendency’, like ‘Relinquishment’ is linked to a hands-on approach to nursing care, and thus to the philosophies of CLIC which have been epitomised through the CLIC ‘Funder’ model. The hands-on approach is associated with specialist nursing tasks from which consultants learn, although POONSs ‘medical’ knowledge is limited. This results in consultants retaining overall responsibility for patients, particularly during a child’s terminal illness and monitoring the work of POONSs. This in turn leads to limited professional autonomy.

**‘Reciprocity’**

Health care professionals at tertiary centres care only for children with malignant disease and their families. This means that, relative to the professional experience of staff at DGHs, families entering the oncology unit will be cared for by health care professionals knowledgeable in childhood cancer. Care is shared between hospital-based health care professionals and POONSs at different stages of a child’s illness trajectory. ‘Reciprocity’ (regardless of the ‘Funder’ model with which regionally-located POONSs are associated) is inherent between members of the oncology team when components of care and ‘ownership’ of patients is shared. This type of partnership therefore differs greatly from ‘Relinquishment’.

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2 The oncology team is defined as senior and junior medical and nursing staff working in OPD and on the ward/s and POONSs. It also includes other members of the multidisciplinary team such as Sargent Social Workers and psychologists.
The ways in which 'Reciprocity' partnerships are constructed vary amongst different groups of regionally-located POONSs and their colleagues. The work of POONSs is either integral and complementary to those who they share care with or care is provided to patients and their families independently of POONSs. These differences account for two sub groups of 'Reciprocity': 'Integrated Reciprocity' which is predominantly linked to partnerships between regionally-based POONSs and senior hospital staff and 'Independent Reciprocity' which, in the main, is identified with partnerships between regionally-based POONSs and junior staff. This section of the chapter discusses features common to 'Reciprocity' regardless of the sub type. Features of this type of partnership are highlighted in Table 12.1. Characteristics which distinguish 'Independent Reciprocity' from 'Integrated Reciprocity' follow on from this.

'Ownership' of Patients

It has earlier been contended that 'ownership' of patients plays an important role in determining the types of partnership which are formed between POONSs and their colleagues. Hence it follows that 'ownership' of patients features in a 'Reciprocity' partnership. Since patient care is shared, albeit at different levels and at different times, between POONSs and other hospital-based health care professionals, it follows that patients are jointly 'owned', with no one group or individual claiming overall ownership of a particular patient. One manifestation of this occurs when POONSs follow up in the community, nursing care and treatment which has been initiated on the ward or in the OPD. As one SN and one Sister best put it:

_I think that (the pain control) was managed on the ward, wasn’t it, with the ward staff and it was liaised with [POONS 1] and [POONS 2] and, you know, they sort of followed him up at home to see if that level of pain control and analgesia was effective... we were sort of assessing him and planning his care on the ward we decided what, you know, what was needed at home, you know, we sort of liaised with the parents and the boy as well, the patient and, and then sort of made contact with [POONS 1] and [POONS 2]_  
(SN12, Southern Regional Hospital)

_I suppose it's backup for the work that we do_  
(Sr6, Northern City Children’s)
Filling Gaps in Services

One consequence of 'Reciprocity' which differs greatly to 'Relinquishment' where other health care professionals are potentially rendered unnecessary, is a recognition by senior staff at regional centres (whose lengthy services predated those of POONSs), that POONSs fill gaps in the services offered by the oncology unit. These gaps were previously unmet or filled by inappropriate or untrained people. One social worker for example confirmed this by explaining that: 'the social worker was sometimes the only person that was the link and often taking medicine out from the hospital' (SW1, Northern City Children’s Hospital). Similarly, although few consultants would have been involved in liaising with community nurses, one consultant at the same hospital suggested that: 'the Macmillan nurses will do the contact with (the hospice nurses) whereas in the past we would have done it' (Consultant 4, Northern City Children’s).

Enhancing the notion of 'Reciprocity' in which it is recognised that POONSs fill gaps in services, some consultants brought about the genesis of POONSs’ services. Consultants with long career histories in the UKCCSG centre in which they work, approached charitable organisations and procured funds to establish POONSs’ posts. One consultant at the Northern City in particular, had also been involved in the selection of POONSs and had managerial responsibilities for them, securing office space and equipment. Being closely involved in establishing POONS services generates collegial relationships between consultants and POONSs which, for consultants, differ to their relationships with ward sisters (see Chapter Nine).

When responsible for initiating POONS services it could be argued that consultants hold a powerful position over POONSs. However this point, it will be argued next, is outweighed by the autonomy possessed by POONSs. Here, their specialist knowledge on which consultants rely, results in nurse-led terminal care and influences treatment-related decisions.
Autonomous Practice and Decision-Influencers

A feature of the relationships between consultants and POONSs which differs greatly to a 'Hierarchical Ascendency' relationship concerns the autonomous practices of POONSs. Here, POONSs do not require or rely on the support and advice of consultants to visit patients in the community. Consultants do not control their work; they therefore possess a high degree of professional autonomy. As one consultant said:

*I don't ask what they've been doing and if they come to me and say, 'I'm going to visit so and so on Thursday', I don't say, 'why'....if they think it's necessary to go and visit so and so they should go and do it*  
(Consultant 5, Northern City Children's)

POONSs connected with this type of partnership not only enjoy professional autonomy but also possess knowledge about shared care and palliative care. In stark contrast to 'Hierarchical Ascendency', this knowledge influences decisions made by others, particularly 'medical' decisions made by consultants. As one staff nurse observed:

*one child was going on holiday and they wanted to put the chemo back a couple of weeks and [POONS 2] spoke up and said, 'look this chemo's going to cause her to be quite achey in her joints, etc., etc., can we put it back?*  
(SN10, Southern Regional)

Whilst a consultant commented:

*now if they (POONSs) say to me, 'oh it's Dr So-and-So at [town] Hospital, we've met with him ....one of the doctors will write and say, 'this one is coming for shared care'*  
(Consultant 7, Southern Regional)
Nurse-Led Terminal Care

Another feature of ‘Reciprocity’ concerns the roles of POONSs and consultants during a child’s terminal care. In contrast to ‘Hierarchical Ascendency’, consultants recognise that POONSs are better suited and are more able to provide and determine terminal care management than themselves: they hand this responsibility over to POONSs, ensuring that terminal care at home is nurse-led. This eases the lives of both senior medical and nursing staff who, due to the constraints of their work, previously visited terminally ill children at home in their own time. Since geography is a major factor in visiting children referred to regional centres, it also ensures that a more equal service is provided to all, not just to those who live in close proximity to the hospital. As one consultant explained:

certainly the families closer to Northern City I would often visit and I very rarely visit a family at home now but I used to visit quite a lot, I mean geographically I was a bit restricted cos it’s a bit daft to waste a day to go all the way to [town], you know I think it’s hard to justify that when you can only do it sort of once perhaps but certainly parents in the more immediate area I used to quite frequently visit at home

(Consultant 5, Northern City)

Furthermore, when POONSs lead terminal care it reassures consultants that care is being co-ordinated, preplanned and controlled, rather than being reactive. As one consultant confided:

just being very personal, in the early days I didn’t sleep very well at night about patients who were at home and terminally ill, I think, you know, now I feel much more comfortable that their needs are being met

(Consultant 7, Southern Regional)
Understanding POONSs’ Relationships with PHCTs

A characteristic of a ‘reciprocal’ partnership which involves SNs, concerns their understanding of relationships between POONSs and PHCTs. Visiting PHCTs and families at home or in local hospitals is the domain of POONSs. However insight into relationships between POONSs and PHCTs is developed and enhanced when ward nurses gain the opportunity to visit PHCTs and families at home, with POONSs. The sensitive nature of POONS’s work means that such visits are usually restricted to junior SNs who are undertaking courses. Staff nurses at both Moorcroft Children’s and the Southern Regional displayed an understanding of the relationships between POONSs and PHCTs. One SN at Moorcroft for example considered: ‘that they liaise quite a lot with GPs, anyway with certain GPs’ (SN4, Moorcroft), whilst another suggested there were sometimes: ‘practical difficulties of getting equipment’ (SN2, Moorcroft Children’s Hospital). Another commented:

*I thought the GP would have more knowledge but obviously he hadn’t looked after a terminal child before and nor had the community nurse, she was absolutely petrified and [POONS I] was there to give her support*  
(SN10, Southern Regional Hospital)

Accompanying POONSs on community visits enhances the degree to which patient care and ‘ownership’ is shared between ward nurses and POONSs. It also enhances relationships between POONSs and SNs and thus ‘Reciprocity’.

In summary, ‘Reciprocity’ exists between regionally-located POONSs and their colleagues, regardless of ‘Funder’ models. There are distinctive features of ‘Reciprocity’ which are apparent between POONSs and senior staff; more particularly between POONSs and consultants. Close relationships develop when consultants have been responsible for initiating POONS services and when POONSs are perceived to plug previously unfilled gaps. More generally, ‘Reciprocity’ is exhibited in shared ownership of patients between all members of staff. ‘Reciprocity’ also exists between POONSs and SNs where SNs possess an understanding of POONSs’ relationships with PHCTs.
'Integrated Reciprocity'

'Integrated Reciprocity', the first of two sub types of 'Reciprocity', exists when POONSs work with other members of the oncology team, acknowledging the roles of others in providing care. In particular, the skills of nurses working within the confines of the hospital are perceived to differ from and be integral to those of POONSs; where any areas of professional overlap do occur, work is negotiated. Although there are features of this type of relationship which pertain to all grades of staff, an integrated approach is particularly evident between POONSs and senior colleagues (consultants and sisters). Such 'integration' spans across each regional centre making this type of partnership indiscernible between either the Macmillan or 'Mixed Funders' models of POONSs. Features of this type of partnership are discussed below and are summarised in Table 12.2.

Working with Sisters

It has earlier been contended that, regardless of the sub-type of 'Reciprocity', an important characteristic concerns shared 'ownership' of patients. A major feature of the way this is manifested in 'Integrated Reciprocity' is through the close professional relationships developed between POONSs and sisters (see Chapter Nine). Here information about patients is shared and exchanged, along with decision-making responsibilities and status. Thus the notion of shared 'ownership' is enhanced. In addition, responsibilities for teaching junior staff are shared.

(1) Sharing and Exchanging Information:
Providing links between the hospital and the community and sharing 'ownership' for children undergoing chemotherapy treatment necessitates communication between sisters and POONSs, who maintain contact with families between hospital visits. Information about patients is shared between POONSs and sisters both in the formal setting of ward rounds and informally. The informality with which information is exchanged between sisters and POONSs, which contributes to shared ownership and thus an integrated approach to 'Reciprocity', is best captured by one sister of an OPD who said:
she comes and asks us whether we've heard anything ...with families that have got problems and she just pops in and talks to us about families that are at home

(Sr6, Northern City Children’s)

Exchanging and sharing information about patients in this way ensures a close, ‘integrated’ relationship between sisters and POONSs and ensures joint ‘ownership’ of patients.

(2) Shared Decision-Making Responsibilities:
A second feature of shared ownership between sisters and POONSs, which contributes to ‘Integrated Reciprocity’ exists when, for example, decisions about patients’ admissions and discharges are required. This results in shared decision-making responsibilities and is important in bonding the relationships between POONSs and sisters. This separates them from junior nurses and frequently junior medical staff, who lack the power to make ‘medical’ decisions. In spite of sharing this power, sisters recognise that POONSs are in a stronger position to be decision makers than themselves: working outside the confines of the hospital gives POONSs greater autonomy.

An example of this feature of ‘Integration’ is best observed in the ‘partnerships’ between the sisters and the POONSs at the Southern who had shared many ‘decision-making’ experiences over the years. Together they had encountered changes in the management of children with malignant disease which had led to changes in practice; they had been involved in developing the paediatric oncology unit and its philosophies; they shared experiences concerning the depletion and subsequent replenishment of both the POONS team and their own numbers, as well as their own professional development. Sharing decision-making responsibilities is reflected by the sister of the ward who said:

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if you've got a patient newly diagnosed and they're in, line, chemo, out in three days, you can't begin to cover it all, and they know you do your best, you know, and if we feel that we can't do it properly and then [POONS 1] cannot, or [POONS 2], can't go into the home, we bring them back to the clinic a bit sooner

(Sr3, Southern Regional Hospital)

(3) Sharing Equal Status:
Sharing decision-making responsibilities with POONSs enables sisters to share equal status with them. Equal status is manifested when sisters see themselves, like POONSs, to possess their own specialist knowledge and skills. This is particularly apparent in high technology areas such as bone marrow transplantation and other specialties such as long-term follow-up clinics. With shared status and specialist areas of knowledge, distinctive boundaries exist between the work of POONSs and the work of sisters. This enhances the abilities of the two groups to share decision-making and to work in an integrated fashion. In sharing status, sisters also see themselves sharing the stresses of responsibility with POONSs, even if the stresses are perceived to be of a different nature. Exceptionally, one of the sisters at the Northern did feel that palliative care and 24 hour on call provision produced greater responsibilities and stresses for POONSs than herself. Generally however, stress is shared between POONSs and sisters. The distinctive boundaries between sisters and POONSs which results in equal status is illustrated by one of the sisters at the Northern who said:

they say, 'look, so that there's only one person doing the liaison it would be better...if just one person does it'...so that's what we tend to do

(Sr5, Northern City Children's)

Thus in 'Integrated Reciprocity' sisters consider themselves of equal status to POONSs; they possess their own areas of expertise which creates distinctive boundaries between their work. Their roles complement each other. Along with equal status, the stresses of responsibility are also shared with POONSs.
(4) Sharing Teaching:
A fourth feature of sharing between sisters and POONSs concerns the 'ownership' of teaching responsibilities. In recognising that both sisters and POONSs develop their own areas of expertise, teaching junior staff (medical and nursing) is shared between POONSs and sisters, depending on the topic. One of the sisters for example talked of her own expertise in the skills required to nurse children undergoing bone marrow transplantation, whilst recognising that POONSs were experts in palliative and shared care. Additionally, several consultants suggested that they would call upon POONSs to teach medical students and junior medical staff about palliative care. The sisters at the Southern particularly talked of both POONSs and themselves having active roles teaching students undertaking post-registration oncology training at the hospital. Although teaching responsibilities may be shared between POONSs and sisters in this type of partnership, POONSs nonetheless take greater responsibility for teaching, since, as acknowledged by the sisters at the Southern, POONSs have additional teaching commitments outside the hospital. Sharing teaching and decision-making augments the notion of an 'Integrated Reciprocity' partnership.

In summary, four particular features depict the close relationships and shared 'ownership' which develop between sisters and POONSs, contributing to the development of 'Integrated Reciprocity'. These include sharing and exchanging information about patients, sharing decision-making responsibilities, sharing equal status and sharing the responsibilities for teaching junior staff.

Shared 'Ownership' of Terminal Care
An additional feature of 'Integrated Reciprocity' between POONSs and senior staff, concerns sharing ownership of terminal care between POONSs and consultants. In this type of partnership consultants (particularly those with a special interest in palliative care) regularly meet with POONSs. This is done both formally at multidisciplinary ward rounds and at weekly or monthly meetings between POONSs and consultants and informally, to discuss and mutually exchange information concerning terminally ill children at home. In addition, one consultant demonstrated 'integration' with POONSs through jointly compiling hospital guidelines for terminal
care and symptom control. When an ‘Integrated’ partnership exists, delegation of work is a two way process between consultants and POONSs. This is illustrated by one consultant from the Northern who said:

this afternoon she popped in to get me to do something

(Consultant 4, Northern City)

In contrast to ‘Hierarchical Ascendancy’ where components of terminal care are also shared between POONSs and consultants, POONSs with an integrated approach to ‘Reciprocity’ judge the necessity of patients’ consultations with consultants. Here, terminal care is nurse led and consultants rarely, if ever, visit children at home; POONSs act as gatekeepers between consultants and families and are responsible for determining the necessity of children’s visits to OPD. Shared ‘ownership’ nevertheless occurs since consultants still assume overall medical responsibility. Consultants feel confident in POONSs abilities to make ‘medical’ decisions and only take back ‘ownership’ of patients when their advice is sought.

Advising Junior Ward Staff about Symptom Management

In addition to the integrated ‘partnerships’ with senior medical and nursing staff, there are some features of ‘Integrated Reciprocity’ which occur between POONSs and junior staff (both medical and nursing). One such trait concerns POONSs advising colleagues on the symptomatic management of terminally ill children. Exceptionally, staff working at Moorcroft perceived POONSs’ knowledge of terminal care to be outstandingly ‘expert’. This creates an ‘Integrated Reciprocity’ partnership between POONSs and juniors on the rare occasions when terminally ill children are cared for in hospital, rather than at home. In this situation expert advice is sought from POONSs by nurses and junior doctors, rather than from consultants. Junior doctors particularly respect their opinions and prescribe medication accordingly:

the kind of input they can have in terms of opiates and things like that ‘cos people tend to shy away from opiates.... and just, you know having her input was so valuable in that respect

(SHO3, Moorcroft Children’s Hospital)
This type of ‘Integration’ between POONSs and junior staff is intensified when newly appointed SHOs starting their paediatric oncology experience, participate in an induction programme. From such programmes an appreciation and early understanding of POONS’s work develops. This generates a close working relationship between themselves and POONSs. In this study, this too was unique to Moorcroft where one of the doctors commented:

*We had an induction week or a couple of days and we met [POONS 3] and sat down and spoke to her, so we knew about the team right from the beginning*  
(SHO 3, Moorcroft Children’s Hospital)

**Negotiated Areas of Work**

‘Integrated Reciprocity’ between POONSs and junior staff also occurs when work is negotiated. In this study three particular examples of negotiation between POONSs and junior staff are apparent. Firstly, negotiation occurs when discharges from hospital are planned between SNs and POONSs. Secondly, negotiated areas of work arise when terminal care at home is shared between POONSs and junior doctors. Thirdly, negotiation develops in areas where primary nursing\(^3\) is implemented.

Care of children at home is incontrovertibly the domain of POONSs. In an ‘Integrated Reciprocity’ approach to partnership, discharge planning is an area in which negotiation arises between ward nurses and POONSs. In this study this feature only arises between POONSs and SNs working at Moorcroft. As one SN explained:

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\(^3\) Primary nursing is a method of organising nursing work. It focuses on the nurse/patient relationship and the autonomous practice of the registered nurse. Patients with chronic illness requiring repeated hospital admissions will be assigned a primary nurse for the duration of their treatment and/or illness. The primary nurse is responsible for co-ordinating 24 hour nursing care. Some primary nurses see this obligation extending into the community between hospital admissions. For those who do, there is the potential for professional overlapping to occur between hospital and community nurses.
In discussion with the Srs.) they have given it back to us, the planning of discharge

(SN3, Moorcroft Children's Hospital)

In this scenario families need little professional support at home between hospital admissions, since parents are taught the nursing skills, by ward staff, required to be the main providers of their child's care. Some families however may require 'specialist' advice at home after discharge from hospital. On these occasions POONSs may provide care at home which has initially been planned by ward staff. Ward nurses recognise that POONSs have greater experience of community care than themselves and so care is 'negotiated'; this requires much collaboration between POONSs and ward staff and close communication thus develops.

'Integration' also occurs when terminal care at home is shared and 'negotiated' between POONSs and junior doctors. This only arose at the Southern where no out of hours cover was provided by the POONS service. Here, negotiation arises when POONSs 'hand-over' terminally ill children at the end of the day and at the beginning of a weekend, assuring that families with terminally ill children and their PHCTs have 24 hour cover from the specialist centre. Since terminal care is nurse-led POONSs must 'negotiate' with SHOs to provide this cover on their behalf. This ensures that POONSs and SHOs work closely together, in 'Integrated Reciprocity'. This is best illustrated by one of the doctors at the Southern who explained:

patients who are being palliated, they would hand over to us at the end of the day or before a weekend, patients who were going to have problems with symptom control, at home.... in the evening... come and have a chat

(SHO5, Southern Regional Hospital)

Whilst such an arrangement could be suggestive of a 'Relinquishment' partnership, 'Integrated Reciprocity' differs in its approach. POONSs in this type of partnership possess the ability and knowledge to predetermine those children whose needs are likely to require 'specialist' input whether from families, PHCTs or DGHs (i.e. have unstable symptom relief or be near to death). Therefore those families whose care is 'handed over' to junior doctors are preselected by POONSs who take overall
responsibility for co-ordinating and managing terminal care. Furthermore negotiation between POONSs and SHOs only arises during terminal care and concerns giving advise and information; it is not task related.

Thirdly, negotiation between POONSs and junior staff occurs in areas where primary nursing is practised. Primary nurses assume 24 hour responsibility for their patients (see Footnote 3). Therefore ‘negotiation’ between POONSs and SNs arises when children are cared for at home rather than in hospital, SNs recognising that POONSs are better placed to provide this care than themselves. This has the effect that information about patients is regularly exchanged between them. At the time of this study only SNs working on one ward at Moorcroft implemented primary nursing. However one SN who had recently returned to work at the Southern where she had worked as a SN some years beforehand, when primary nursing had also been employed, reflected on how primary nursing brought about close relationships between POONSs and SNs:

…it was totally different…we could you know, every day nearly I’d speak to her if she was on the unit, I’d go into her office and she’d just be there, so you could say, oh you know, ‘what about this’ (SN11, Southern Regional)

The importance of primary nursing in ‘Integrated Reciprocity’ is that it encourages SNs with a commitment to their primary patients, to approach POONSs directly to exchange information, thereby developing a close partnership between them.

In conclusion, ‘Integrated Reciprocity’ exists when regional POONSs work alongside their hospital-based colleagues with each recognising the importance of individuals’ roles. This type of ‘Reciprocity’ is an example of the partnerships which form between POONSs and senior staff. It is particularly evident between POONSs and sisters who regularly exchange information about patients and share responsibilities for making decisions about their management. They also share equal status and responsibilities for teaching junior staff. ‘Integrated Reciprocity’ also occurs when POONSs share responsibility for providing terminal care at home, with consultants.
There are, however, occasions when 'Integrated Reciprocity' arise between POONSs and junior hospital staff. These include two different examples of POONSs working closely with junior staff to provide terminal care, one to children receiving care in hospital, the other at home. This type of partnership also develops when ward nurses are responsible for discharge planning and where primary nursing is implemented.

**'Independent Reciprocity'**

A second type of 'Reciprocity' also emerged, referred to as 'Independent Reciprocity'. This differs from an integrated approach since, although patient care is similarly shared between POONSs and other members of the oncology team, limited recognition of roles or contact exists between POONSs and those others with whom the care is shared. This type of partnership is primarily displayed through the limited interactions between junior staff and POONSs at regional centres, regardless of the 'Funder' model with which they are associated. There is however, one unusual example where this partnership occurs between POONSs and senior colleagues. Features of this 'partnership' type are summarised in Table 12.2 and are discussed in detail below.

**Limited Contact between POONSs and Junior Staff**

A major component of 'Independent Reciprocity' includes limited contact between POONSs and other members of the oncology team. This most commonly occurs between POONSs and junior staff. An example of this arises between POONSs and SNs where POONSs rarely advice on aspects of in-patient care. Here, contact between SNs and POONSs may be limited to times when POONSs visit the ward to meet new families prior to their discharge. The geographical layout of an oncology unit may be such that the ward, day centre, out-patients and offices are located within the same vicinity, such as at the Southern. However where an 'Independent' partnership develops, SNs consider that the POONSs' office, even when located within the boundaries of the paediatric oncology unit, is too remote for frequent contact. In this scenario an 'out-of-sight-out-of-mind' relationship occurs, enhancing the notion of 'independence'. As one SN at the Southern admitted:
You can think of something when you see them .... or when we’re sitting in the coffee room and something will be brought up.. about a child’s care at home, bla, bla, bla and things will get talked about, but really, you know, if they’re not about and you can’t see them and, you know, you might think, ‘oh yeah, I must go and see [POONS 1]’ and things like that, you know, but she’s not there to sort of jog your memory so -  

(SN12, Southern Regional Hospital)

In this type of ‘partnership’ sisters with a more integrated relationship with POONSs act as go-betweens, relaying information between POONSs and SNs. Staff nurses commonly feel bypassed and any direct communication between SNs and POONSs is written rather than verbal. This creates distance, confusion and presumptions between themselves and POONSs. One SN captured this best:

…like when Jacob went home I just wrote a note in the book saying, ‘[POONS 1] following up’ and I didn’t even realise she’d seen him... and then I read a note saying oh yes, there’s a note saying that, but no-one - and I mean to this point I don’t know whether she did see him on the unit or, you know

(SN11, Southern Regional Hospital)

Contact between SNs and POONSs is also limited where twelve hour shifts⁴ are in operation. This system restricts the number of days worked during any one month since fewer, longer days are worked by ward staff. Few SNs interviewed in this research worked this system. Those who did however, suggested that it adversely affected their relationships with POONSs. Twelve hour shifts afforded them little opportunity to have contact with their ‘named’ patients, this in turn impinged on the necessity for contact with POONSs. As one SN at Moorcroft explained:

one of my children came in, one of my named patients and I just missed him and I was working on the other part of the ward, I was doing that and then I was nights off, I saw him briefly in the corridor

(SN2, Moorcroft Children’s Hospital)

⁴ Twelve hour shift systems were condemned at the 1996 RCN Congress as ‘damaging to staff and patients’.

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Senior house officers are employed in a variety of positions and the type of work they undertake influences their contact with POONSs (see Chapter Eight). Some in this study for example worked predominantly in OPD whilst others worked on the wards. This affected the degree of contact between themselves and POONSs. As one explained: 'because I’m not on the ward as often as [SHO3] I don’t see them... but if I need them I will call' (SHO 4, Moorcroft Children’s). In spite of varying levels of contact between POONSs and SHOs, communication between POONSs and SHOs remains limited compared to that of their senior colleagues, linking them with an ‘Independent Reciprocity’ approach to partnership. Limited contact between POONSs and SHOs is highlighted by one SHO who said:

we don’t really have much contact with them other than weekly ward rounds where they have their input for the community patients

(SHO1, Northern City Children’s)

As intimated above, the main time for contact between SHOs and POONSs is during multidisciplinary ward rounds. Where ‘Independent Reciprocity’ exists information imparted by POONSs at these meetings is of limited value to SHOs, since the patients discussed are frequently unknown to them. This occurs either because SHOs have no part in the management of terminally ill children at home, as was the case at the Northern, or because POONSs have limited responsibility for in-patient care, as at both the Southern and the Northern. These points have been reflected by two SHOs at the aforementioned hospitals:

In terms of direct communication we’ve, we’ve had almost no reason so far to specifically ask or tell each other anything. I’m very aware of their presence... they’re present at all of the ward rounds and all the hand-overs in the morning and so on

(SHO 6, Southern Regional Hospital)

I suppose the stuff they hand over on the ward round I suppose is mainly the terminal, near terminal patients that they have been out to see

(SHO 1, Northern City Children’s)
In summary, limited contact exists between POONSs and some groups of SNs and SHOs. This is particularly the case when POONSs have limited involvement with in-patient care, as observed at both the Southern and the Northern, when twelve hour shifts are worked by SNs and when communication between POONSs and SNs is written rather than verbal. When formal contact is established between POONSs and SHOs, the information they reap may be of little relevance. In these situations an independent form of ‘Reciprocity’ arises.

Duplicating Work
When SHOs do not participate in a formal induction programme, as in more ‘integrated’ partnerships, and have limited contact with POONSs, little understanding about POONSs’ work is gained. Without such insight SHOs work independently of POONSs. One of the consequences of this is the potential for SHOs to unknowingly overlap and duplicate work carried out by POONSs, repeating tasks such as conveying information about children to local hospitals. An example of this is given by junior doctors at the Northern City Children’s Hospital. Due to their lack of insight about the operation of MPNs within their hospital, SHOs believed that MPNs only provided services to terminally ill children at home and their families. Senior staff with more ‘integrated’ relationships, talked of the important role MPNs played in facilitating shared care between Northern City and DGHs who referred children to the unit. Consequently, whilst one SHO talked of the amount of time spent liaising with local hospitals prior to a child’s first discharge, senior medical and nursing staff commented that POONSs did the same. This is best illustrated by the aforementioned SHO who said:

‘if they’re (linking with shared care hospitals) I’m not aware they’re doing it…..maybe there are things they’re happy to do and we don’t know, sort of thing’

(SHO1, Northern City Children’s)
Recapitulating, ‘Independent Reciprocity’ primarily exists between POONSs and junior hospital staff working at regional centres, regardless of the ‘Funder’ model with which POONSs are associated. This type of partnership develops through limited contact between POONSs and some junior staff and limited understanding by SHOs of the work that POONSs do. This in turn leads to the potential for SHOs to duplicate tasks undertaken by POONSs. POONSs and junior staff work in ‘Reciprocity’ unintentionally, each co-existing independently.

‘Ownership’ of Terminal Care
An unusual example of ‘Independent Reciprocity’ occurs between POONSs and consultants when POONSs are perceived to be the experts in palliative care. Here, palliative care is governed entirely by POONSs and terminally ill children are ‘owned’ by them. This means that POONSs do not look to consultants for advice and make any ‘medical’ decisions that are required. Contact between POONSs and consultants is consequently minimal. This scenario is unique to the partnerships between POONSs and consultants at Moorcroft Children’s Hospital. One consultant explained:

\textit{once a child, his illness has progressed where there are fewer acute therapeutic medical, therapeutic medical issues then the vast majority of the management of the child gets taken over by POONSs... it’s actually passing the baton of responsibility with you know, there is a period of time when you know the runners have actually got it both in their hands but there’s often the passing on of that clinical responsibility}

(Consultant 1, Moorcroft Children’s)

In this type of partnership, ‘ownership’ of terminally ill children at home, by POONSs, is further strengthened when POONSs hold their own meetings to which consultants are invited (although rarely attend). This is the central time of the week when particular problems encountered by terminally ill children and their families, or by POONSs, are discussed. This is an unusual feature in the relationships between POONSs and senior medical staff since information about terminally ill children at home, as already highlighted above, is more usually exchanged at multidisciplinary ward rounds which are led by consultants. Although some regret was expressed by
consultants concerning this loss of control, POONSs in this type of partnership are held in very high regard and consultants see themselves to lack the skills and time to provide satisfactory palliative care. The consultant who used the relay race to metaphorically describe changing ownership continued:

*I don’t think I’m alone in thinking that one loses touch with what’s happening sometimes to patients who are at home, you don’t end up with a real feel for what’s going on…. although it sounds a pretty rotten thing to say, I suppose you have to admit it, that none of us (consultants) actually really have got time or the skill to do it as well as you would want to do it in an in-patient setting*

(Consultant 1, Moorcroft Children’s)

To recap, ‘Independent Reciprocity’ primarily exists between regionally-based POONSs and junior hospital staff because they have limited contact with each other. However it also develops between POONSs and consultants when POONSs are seen to possess exceptional expertise in palliative care. Here, ‘ownership’ of terminally ill children and their families is passed almost entirely to POONSs who maintain overall responsibility for care, holding weekly meetings to which consultants are invited. Contact between POONSs and consultants is consequently minimal in this type of partnership.

**Conclusion**

The previous chapter defined three different types of relationship between POONSs and PHCTs of which one is ‘Partnership’. In examining relationships between POONSs and hospital-based health care professionals, this chapter has suggested that the nature of hospital admissions inherently breeds ‘partnerships’ between professionals. Consequently, a partnership typology between POONSs and hospital-based health care professionals has been outlined in this chapter. This typology is influenced by the work location of POONSs (itself affected by the strategies of charities funding their posts), the ‘ownership’ of patients and their care, and the degree to which terminal care is nurse or doctor-led.
Four types of partnership have been highlighted: 'Relinquishment', 'Hierarchical Ascendancy', 'Integrated Reciprocity' and 'Independent Reciprocity'. 'Relinquishment' and 'Hierarchical Ascendancy' are associated with POONSs who provide hands-on care to children in hospital and are identified with partnerships between district-based POONSs and their colleagues. These 'partnerships' are therefore predominantly associated with the strategies adopted by CLIC. Where 'Hierarchical Ascendancy' differs from 'Relinquishment' is that the former contains a power element in which consultants oversee and, in part, control the work of POONSs. In 'Relinquishment', 'ownership' of patients and their care is perceived by ward staff to lie with POONSs. In reality, consultants retain 'ownership' and are responsible for making decisions about patient care (particularly during terminal illness). Terminal care particularly therefore, is medically-led. It is probable that a combination of limited 'medical' knowledge acquired by POONSs at DGHs, the presence of CLIC-funded associate specialists and a more traditional culture of 'nurse/doctor' relationships at provincial hospitals (Mackay 1993, Porter 1995) is responsible for the element of control which exists over district-based POONSs, particularly those funded by CLIC.

'Reciprocity' exists between all hospital-based health care professionals and POONSs at regional centres, since each member of the oncology team provides care to children with malignancy and their families at varying times. Here, 'ownership' of patients is shared equally but terminal care is co-ordinated by POONSs. This suggests that the work location of POONSs at regional centres overrides the influence of funders in developing partnerships. Nevertheless, 'Reciprocity' is not uniform and two sub types are apparent: 'Integrated Reciprocity' and 'Independent Reciprocity'. 'Integrated Reciprocity' predominantly occurs between POONSs and senior members of staff whilst 'Independent Reciprocity' exists, in the main, between POONSs and junior colleagues. However there are features of both types of 'Reciprocity' which include junior and senior personnel. The degree and nature of contact between POONSs and their colleagues appears to influence whether 'Independent' partnerships are formed with senior staff or 'Integrated' partnerships with juniors. However it is probable that local culture and personalities of both POONSs and their colleagues play a major
factor in influencing 'Reciprocity' types. What is apparent from both stages of the research is that different 'partnerships' are developed between senior doctors and nurses compared to those with junior staff, regardless of work location or funder of POONSs. In particular, the POONS data set suggests that no POONS works as closely with junior medical staff as they do with their seniors (see Table 12.4), whilst the case studies, with one exception, support this.
PART THREE - THE CONCLUSION
Chapter Thirteen - Drawing the Threads Together

Introduction
Health care reform during the 1990s, arising from the White Paper *Working for Patients* (DoH 1989a), has been driven by the ethos of a market-driven economy. Such change has brought about a mixed economy of health, reminiscent of health care delivery prior to the inception of the NHS. This has resulted in a health service in which the boundaries between the private, voluntary and public sectors have become increasingly blurred (e.g. Mohan 1991 & 1995, Appleby 1992, Mayo 1994). This being so, increased reliance has been placed upon the voluntary sector as a source of generating income to support the services provided through the NHS (Mohan 1991, Black 1994). Although these income generation initiatives have not been as successful as earlier anticipated (Mohan 1995), childrens' services have fared better than other areas of health care (Brenton 1985, Mohan 1995)(see Chapter Two). Disease-specific childrens' charities are particularly popular with the British general public, of which childhood cancer is probably the most emotive. Thus, one area in which funding from the voluntary sector has been particularly successful has been the establishment of clinical nurse specialists working with children with cancer in the community (POONSs). The consequential partnerships that have developed between the voluntary and the public sectors has provided the background to this thesis. It is this central theme which is explored in order to draw the threads of the research together in this concluding chapter.

This study has suggested that there are problems for health care professionals when a mixed economy of health care exists. These problems have been examined through exploring the structure, organisation and practices of POONSs and the relationships they develop with other health care professionals. In order to address these issues a triangulated methodology was adopted. Firstly, to describe the structure, organisation and practices of POONSs and to elicit the effects of divergent strategies upon these elements of POONS work, a semi-structured survey was designed and conducted with all POONSs throughout the UK and Eire in 1993. Three ‘Funder’ models of POONSs emerged from analysing this phase of the research: the CLIC model, the Macmillan
model and the 'Mixed Funders' model. Secondly, to determine the effects of charities' strategies on the types of relationships developed between POONSs and their colleagues, a qualitative case study approach was adopted. During this phase of the work focused, in-depth, tape-recorded interviews were conducted with a wide variety of health care professionals working with POONSs, across both community and acute hospital settings, at three locations. The three sites were selected to represent the three 'Funder' models associated with POONSs.

My research has begun to indicate that who funds POONS posts affects the practices, organisation, structure and professional relationships between POONSs and other health care professionals. Thus the mixed economy of health care, observed through studying POONSs, has a major impact not only on the ways in which nursing services are delivered but also on the types of relationships that are formed between groups of health care professionals. From this, policy, practice and theoretical conclusions may be drawn. Whilst both theoretical and policy contributions are interlinked, this final chapter draws conclusions in three parts. Firstly, the contributions this research makes towards developing sociological and nursing theory will be discussed. At a macro level, this section of the chapter contributes theoretically to a debate within the sociology of the professions about professional knowledge and status. It contends that, through studying POONSs, the significance of intraprofessional specialisation and experience in developing professional knowledge becomes apparent. In so doing, it informs the debate on the 'professional project' of nursing. Similarly at a macro level, this chapter furthers the understanding of relationships between specialist nurses and other health care professionals and contributes to our theoretical understanding about relationships between specialist nurses and other nurses. It does the latter firstly, through adding to the existing knowledge about relationships between community nurses and CNSs. Secondly, and more importantly, it opens a debate on relationships between CNSs and hospital-based nursing staff. Finally, theoretical contributions will be made towards understanding the concepts of partnership and empowerment.
The second section of the chapter draws conclusions for practice and policy. Here, the ramifications for families, managers, health economists and policy makers at both micro and macro levels are discussed. The final section of the chapter discusses the changes in POONS services which have occurred during the period in which this study was conducted and draws conclusions for the future.

**Typologies of Professional Relationships**

Two professional relationship typologies have been developed in this thesis: one between POONSs and primary health care teams (PHCTs) (see Chapter Eleven) and a second between POONSs and other hospital-based health care professionals (see Chapter Twelve). The former typology highlighted three types of relationship: ‘Empowerment’, associated with a hands-off method of care; ‘Disempowerment’ where hands-on nursing care is provided to children by POONSs, and ‘Partnership’ involving a mixed hands-on and hands-off approach. This typology primarily arose from the divergent strategies of the two main charities funding POONS posts: the empowering ideals of CRMF led towards an empowerment type of relationship with PHCTs, whilst the hands-on approach adopted by CLIC inclined towards disempowerment. Although no explanation for a partnership type of relationship was proffered, it is probable that this type of relationship (associated with a ‘Mixed Funders’ model of POONSs) develops between POONSs and PHCTs when health care professionals, rather than charities, influence the organisation of POONS services (see Chapters Three, Six & Eleven).

A second typology took the premise that partnerships are inherent amongst hospital-based health care professionals. In so doing, the nature of the relationship between POONSs and other hospital-based health care professionals was examined in the data and four types of ‘partnership’ were developed. Two of these partnerships were associated with the CLIC model: ‘Relinquishment’, connected with handing over the care of children from POONSs to ward staff only in the absence of POONSs, and ‘Hierarchical Ascendancy’ where consultants control POONSs’ work. These relationships developed between hospital staff and POONSs at DGHs and arose from CLIC’s ideals to fund nurses providing all-encompassing care, limited ‘medical’
knowledge being acquired by POONSs at DGHs, and the prevalence of more traditional nurse/doctor cultures in DGHs in which consultants exert authority over nurses. Two different ‘partnerships’ were associated with hospital staff and POONSs at regional centres, where all staff carry responsibility for providing care to children with malignant disease: ‘Integrated Reciprocity’ where POONSs and hospital-based colleagues share ‘ownership’ of patients, mindful of each others’ roles, and ‘Independent Reciprocity’ where POONSs and other hospital staff share ‘ownership’ of patients but are sometimes oblivious of each others’ functions. It is probable that local culture and personalities of both POONSs and their colleagues play a major factor in influencing these two ‘Reciprocity’ types, rather than being directly attributed to the strategies of charities associated with regionally-located POONSs.

‘Integrated Reciprocity’ more commonly occurred between POONSs and senior hospital staff, whilst ‘Independent Reciprocity’ more usually equated with the relationships developed between POONSs and junior colleagues. However, there are examples where these relationship types were reversed (see Chapter Twelve). When ‘Integrated Reciprocity’ arose between senior medical staff and POONSs at one location, it did not occur in the same location between POONSs and junior personnel. This was the same for ‘Independent Reciprocity’. It is therefore possible to conclude that POONSs can only develop a close ‘Integrated’ relationship with either senior or junior medical staff; they are unlikely to develop this type of relationship with both. The reason for this is unclear but may lie in the perceived levels of knowledge of POONSs and their decision-making responsibilities. For example, where POONSs are perceived to be extremely knowledgable (e.g. in terminal care), their knowledge may be seen to outweigh that of consultants. Integration between consultants and POONSs is therefore unnecessary since decisions about care (a key determinant in the ‘ownership’ of patients and the relationships which form between POONSs and their colleagues) are determined by POONSs, with little or no requirement for medical supervision. This negates integration (i.e. communication) between consultants and POONSs but ensures integration between POONSs and junior staff, since the junior staff actually deliver the hands-on care and require supervision of terminally ill children from the most expert sources.
Since both the work location of POONSs (a major determinant in the nature of partnerships between POONSs and hospital staff) and the degree of hands-on care provided by them (influencing the relationships between POONSs and PHCTs) are affected by the philosophies of charities funding POONS posts, it is concluded that mixed funding sources of POONSs have influenced the construction of these relationship typologies. At a sociological level, the findings from this study suggest that a mixed economy of health care may influence the types of relationships developed between groups of health care professionals, whilst at a macro level, there are implications for all public sector professionals affected by mixed funding sources. These typologies contribute to an understanding about professionalization, interprofessional relationships, relationships between specialist nurses and other nurses and the concepts of empowerment and partnership. They are therefore drawn upon throughout this chapter.

**How Does the Mixed Economy of Care Influence Professionalization?**

Professionalization has been described as: *'the process by which an occupation develops the characteristics of a profession'* (Hamilton 1992:32). The process of achieving professional status is complex and is compounded by a lack of definitive agreement as to the meaning of 'profession'. However, sociologists frequently agree that professionals are viewed as homogenous groups (see Chapter Four). From a distance POONSs demonstrate features of professional cohesiveness, enhancing the professionalization of nursing in general and this specialty in particular. However, on closer inspection, the mixed funding sources of POONSs lead them to function as a fragmented occupational group, hindering the 'professional project' (Larson 1977, Walby et al. 1994, Macdonald 1995) of nursing. This section of the chapter discusses the limited features which contribute towards making POONSs an homogenous professional group. More significantly, it deliberates how the mixed funding sources of POONSs underpin the ways in which POONSs function as a fragmented nursing group, hindering the current professionalization drive in nursing.
Towards Professionalization

POONSs have previously been described as sharing common functions such as bridging gaps in services and collective aspirations, such as ‘befriending’ families (Bignold et al. 1994a, 1995b). These common aspects which contribute to the development of professional cohesiveness are reflected in the shared endeavours of charities funding their services, to provide the best possible service to families of children with cancer. This research suggests that there are further features which unite POONSs, indicating that a degree of cohesion amongst the group has been achieved, assisting along the pathway to professionalization. These are discussed below.

(1) The Acquisition of an Acronym:
Prior to the outset of this research, no collective term existed for the group of specialist nurses who cared for children with cancer and their families, in the community. Through disseminating the findings which contributed towards this research (Hunt 1996) and the work of Bignold et al. (1994a, 1994b), the group of CNSs who undertake this type of work have collectively acquired the acronym ‘POONS’. This acronym has subsequently become widely recognised within paediatric oncology settings and unites all nurses in this specialist field.

(2) POONSs as ‘Specialists’:
Regardless of which organisation funds POONSs and where they are consequently located, a feature of being a POONS is that they are all regarded as specialists within their field; how this field is defined varies however and is dependent upon the degree of experience individual health care professionals have themselves gained in childhood malignancy (see Chapter Ten). In other words even though district-based POONSs may not be as knowledgable or experienced as some junior nurses working at regional centres, they have gained more experience than other district-based acute hospital staff and PHC professionals. They are therefore perceived to be more knowledgable and ‘specialist’ than those they work with. Hence, ‘specialist’ status is shared by all POONSs regardless of the degree to which they have developed their own skills and knowledge, enhancing professional cohesiveness.
(3) Bridging the Gaps with an On-call Service:
The provision of an on call service, by the majority of POONSs, assists in bridging the gap in knowledge which exists between the community and the acute hospital sector (whether regional or district), regardless of how and to whom it is provided. Whether PHCTs work in an environment where district-based POONSs practice or where regionally-located POONSs are available, PHCTs’ previous experiences of childhood malignancy are likely to be similarly limited. Therefore regardless of the degree of expertise developed by POONSs, on-call services provide PHCTs with a ‘specialist’ service. The availability of an on-call service, regardless of the information obtained by PHCTs, unites all POONSs.

(4) The ‘POONS Personality’:
In spite of nursing’s continuing attempts to professionalise and the recognition that CNSs should be highly experienced and trained beyond the level of registration, this study recognises the continuing importance of the ‘right’ personality. Personalities have often featured in analyses of CNSs; for example they have often been singled out from other groups of nurses through their possession of dynamic personalities and excellent communication skills (Riehl & McVay 1973, Hamric & Spross 1989, Miller 1995, Arnfield 1996). The death of a child may be an extreme emotional challenge to health care professionals inexperienced in this field. It is not surprising therefore that the ‘right’, ‘rounded’ and ‘matured’ personalities of POONSs have been given great importance in this study by the respondents, regardless of the location at which they are based, the nature of the personality or the funding organisation with which they are associated. Thus the ‘POONS personality’ is an additional feature which depicts POONSs as a cohesive group.
Hindering Professionalization

Despite depicting elements of professional homogeneity, varying charities' strategies have resulted in divergent working practices, the development of different types of relationships with other health care professionals and varied levels of knowledge amongst different groups of POONSs. Such differences undermine the formulation of a recognised, cohesive professional group of Clinical Nurse Specialists. These differences outweigh the features of commonality amongst POONSs already outlined, hindering the professional project of nursing. Elements of POONS services and practice which hinder further drives towards professionalization are discussed below.

(1) Lacking Definitive CNS Traits:
Long standing debates have identified difficulties in clarifying the role of the CNS (see Chapter Two). Equally, recent problems have arisen distinguishing between advanced nurse practitioners and CNSs (e.g. see Castledine 1996, Castledine et al. 1996, Coyne 1996, McGee et al. 1996, Mills 1996). Nevertheless, there are recognised tenets of a CNS rôle which include participating in research activities, educating other members of staff and acting as resource agents (Miller 1995). This research has suggested that not all POONSs function under these tenets: CLIC nurses in particular do not participate in research activities, educate other members of staff and rarely act as resource agents to other health professionals. Mixed funding sources of POONSs therefore undermine their ability to operate as an homogenous group of CNSs, hindering attempts to professionalize this group of nurses.

(2) Approaches to Nursing Care:
Fragmentation, hindering professionalization, is further exhibited through the existence of three different 'Funder' models of POONSs (see Chapter Six). These models have evolved through the divergent strategies of charities associated with funding POONS posts and differ greatly in the ways in which their services are structured, organised and delivered. At one end of a continuum, the Macmillan model is identified with a hands-off approach to nursing care, whilst at the other, the CLIC model is associated with hands-on nursing care. These different approaches to nursing do little to unify this group of specialist nurses.
(3) Types of Relationship with Other Health Care Professionals:
Heterogeneity of POONSs is also portrayed through the development of a complex structure of relationships developed with other health care professionals across both community and acute hospital settings (see Chapters Eleven & Twelve). The influences that mixed funding sources have upon the different types of relationships, discussed earlier in the chapter, act as a major inhibitor of professional cohesion amongst POONSs.

(4) Knowledge Discrepancies:
A characteristic which further hinders the professional project of nursing concerns the discrepancies in the knowledge of POONSs. This research has suggested that the mixed funding sources of POONSs influence not only the different professional qualifications attained by POONSs but also the level of experience gained and sustained by POONSs (see Chapter Ten). In particular, it argues that POONSs funded by CLIC acquire limited professional experience and qualifications and, due to the DGH location of their posts and the small numbers of children they encounter, have difficulty sustaining previously acquired knowledge. The demands placed upon POONSs by CRMF, mean that MPNs attain specialised professional qualifications not sought by nurses funded by other bodies. These different levels of knowledge create divisions amongst POONSs further undermining the professionalization of nursing.

(5) Financial Rewards:
Discrepancies in the financial rewards of professionals have long been noted by sociologists (Larson 1977). Acquiring Trust status gives hospitals the flexibility and freedom to regulate staffs' salaries, causing disparities in the salaries of health care professionals in similar positions, working in different hospitals. This situation is compounded by the mixed economy of care where charities also influence the salaries of professionals. This has been observed through the inconsistent grades attained by POONSs and by the particular variance in the grades of CLIC nurses (see Chapter Six).
In conclusion, to answer the question posed in the title of this section of the chapter, through studying POONSs I contend that a mixed economy of care hinders the professionalization of nursing. Taking the premise that professionals are viewed as members of homogenous groups, mixed funding sources thwart CNSs’ attempts to be viewed as a cohesive professional group. Whilst professional cohesion is apparent at a superficial level, professional homogeneity is largely prevented by the strategies of the funding organisations associated with POONSs. This arises in particular through different models of POONSs, different relationship types and varying levels of knowledge. If POONSs wish to professionalise they need to do two things. Firstly, they need to resist the demands of a mixed economy of care which fragments them. This can only be achieved by overriding the demands placed upon them by the charities who fund their work and the requirements of their managers, eager to find alternative sources of funding in a climate of increasing financial pressures. Secondly, they need to not just accept being more knowledgable than the health care professionals they work with; they need to strive for consistent levels of knowledge. This would imply that all POONSs should be located at regional centres so that they can maintain a level of professional and practical expertise, unattainable at DGHs.

**Theorising ‘Specialist Knowledge’**

This section of the chapter discusses the contributions the research makes to the sociology of the professions through examining ‘specialist knowledge’. In so doing, it suggests that intraprofessional specialization and experience, previously overlooked within sociology, play a major role in ‘professional knowledge’. Secondly, it argues that specialist knowledge plays a significant part in determining how professional relationships are formed. Finally it is contended that when nurses possess greater specialist knowledge and experience than doctors, the boundaries which exist between nursing and medicine, become increasingly blurred. This exacerbates the enduring problem in defining a ‘profession’.
Nursing assumes that baseline knowledge acquired through professional training, is only a building block on which to develop further knowledge and skills, before becoming 'expert'. In contrast, sociology has hitherto pictured specialist knowledge as that which separates one profession from another, viewing professionals as homogenous groups; knowledge has consequently been viewed only from a baseline perspective (see Chapter Four). A problem therefore thrown up from the findings of this study is that no previous sociological examinations of the professions have explored knowledge beyond it's prerequisite for attaining professional status. This study suggests that baseline education ill equips experienced professionals to actively participate in care in specialised areas. Furthermore, undertaking post basic qualifications and gaining experience are essential for acquiring specialist knowledge. Such requirements have been demonstrated in this study through both primary and secondary health care professionals, experienced in their own fields of practice, acknowledging that POONSs possess specialist knowledge and skills which they themselves lack, and which are required to actively participate in the care of children with malignant disease. These components of 'specialist' knowledge have also been displayed by POONSs themselves who demonstrate differing degrees of knowledge through the variation in their qualifications and experiences (Chapter Ten).

Previous work in sociology of the professions failed to recognise the importance of knowledge within any given profession and the importance this has for structuring professional relationships. Findings from this study suggest that this is naive and that further elaboration of the concept of knowledge develops an understanding of how professionals relate within professions and across affiliated professions. Furthermore, an understanding of how specialist knowledge is constructed by professionals is of vital significance to the ways in which these relationships are formed. These points have been illustrated by the discernible existence of a partnership typology between POONSs and hospital-based health care professionals (see Chapter Twelve) and by health care professionals' perceptions of 'specialist' knowledge (see Chapter Ten). 'Partnerships' are grounded in the 'ownership' of patients and the degrees to which patient care is nurse or doctor led. 'Ownership' of patients, is in turn, determined by the degrees to which POONSs are perceived, by their colleagues, to be knowledgable.
Hence, specialist knowledge underpins the types of relationships formed between POONSs and other health care professionals.

This study has also problematised the role of knowledge in professional identity. In suggesting that POONSs are, in many cases, more knowledgable about aspects of paediatric oncology than the doctors they work with, the pre-existing grey areas between nursing and doctoring are intensified. This is exemplified by POONSs who develop an 'Integrated Reciprocity' relationship with junior medical staff, both 'Partnership' and 'Empowerment' relationships with GPs and most particularly when an 'Independent Reciprocity' relationship is developed with consultants. Here, POONSs are perceived by medical staff to possess more knowledge about terminal care than themselves; they make 'medical' decisions about patients, giving power to POONSs over their medical colleagues. It is this position of power which undermines medicines traditional power over nursing, aggravating the pre-existing difficulties defining 'profession' (see Chapter Four). These points are discussed further in the following section.

In conclusion, findings from this study indicate that the acquisition of specialist knowledge is complex and is not just grounded in baseline professional qualifications. Experience is also important in establishing specialist status. Furthermore, specialist knowledge is not merely dependent upon the nature of the profession i.e. medicine or nursing but determined by the nature of the intraprofessional specialty. In this instance specialist knowledge is determined by those who have gained knowledge about childhood cancer (both doctors and nurses) compared to those who have not obtained such knowledge (both doctors and nurses).

**Interprofessional Relationships**

This section of the chapter discusses the theoretical contributions the research makes towards understanding interprofessional relationships. The system of health care in which children with malignant disease are treated, and the influences of mixed funding sources, has resulted in a complexity of relationship types between POONSs and others with whom they work (see Chapters Eleven & Twelve). Although recent
studies suggest that the balance of power is shifting away from doctors to nurses to develop 'negotiation' (Svensson 1996), doctors still retain positions of power, with nurses seldom achieving 'formal overt decision-making' relationships with doctors (Porter 1991, 1995) (see Chapter Four). This power relationship is exemplified in this study through 'Hierarchical Ascendency' in which some senior medical staff retain overall 'ownership' of patients and control over the work of POONSs (see Chapter Twelve). However this type of power relationship was confined to POONSs in DGHs and as suggested earlier, may be entrenched in the more traditional doctor/nurse relationships associated with provincial hospitals (Mackay 1993, Porter 1995).

In contrast, 'authority' of SHOs working at DGHs is undermined in 'Relinquishment'. Here, SHOs not only lack the ability to 'negotiate' care with POONSs due to their lack of specialist knowledge, but they potentially become deskillled - hands-on tasks traditionally provided by junior medical staff to children in hospital with malignant disease, are instead provided by POONSs when on duty rendering them, for the most part, superfluous. It is probable that by denying such experiences to SHOs undergoing GP training, long term detrimental effects may be experienced when, as GPs, these doctors encounter a child with malignant disease.

More usually relationships between POONSs and doctors are egalitarian. Here, not only is 'negotiation' (Svensson 1996) exhibited but 'formal overt decision-making' (Porter 1991, 1995) is achieved by POONSs. This type of relationship is epitomized when POONSs develop 'Integrated Reciprocity' relationships with both junior doctors and consultants (Chapter Twelve) and 'Partnership' with GPs (Chapter Eleven). In particular, egalitarianism is depicted in the shared responsibilities and 'ownership' of patients by POONSs and consultants in 'Integrated Reciprocity'. In each of these relationships doctors lack the hitherto traditional power over nurses.

Formal overt decision-making relationships are further depicted when POONSs develop an 'Empowerment' type of relationship with GPs (Chapter Eleven). This type of relationship extends beyond negotiation since GPs lack the specialist expertise to negotiate with POONSs, and so POONSs are in an 'empowering', and therefore
powerful position. A more extreme shift in the power balance between doctors and nurses has been exhibited in this study through the development of 'Independent Reciprocity' relationships between POONSs and consultants. POONSs who develop this type of relationship with senior medical staff have achieved greater degrees of 'specialist' knowledge than their medical colleagues. Here, 'ownership' of patients is passed from the consultant to the CNS who becomes responsible for the 'medical' decisions. When this occurs not only do nurses hold greater decision-making powers than their medical counterparts in relation to the terminal care of children with cancer, but they control care at a higher level, with the power to 'invite' consultants to meetings at which terminal care is discussed.

This research contributes to the continuing erosion of the 'doctor-nurse' game' (Stein 1967, 1978) which has been much in evidence in recent decades (see Chapter Four). Not only has power, once possessed by junior doctors, disintegrated but this study suggests that 'formal overt decision-making' relationships between POONSs and consultants are much in evidence. The greatest contribution however, that this study makes to understanding the doctor/nurse relationship, is in the shift in power from doctors to nurses which exists between consultants and POONSs in 'Independent Reciprocity'. Although, this type of relationship was unusual, it is an indication that nursing is continuing to move along a more equal path with medicine.

**Intraprofessional Relationships**

A review of the literature revealed an absence of sociological research on the relationships which develop among groups of nurses. Furthermore, there is a paucity of nursing literature in this area (see Chapter Four). Mixed funding sources of POONSs have influenced the variety of relationship types between POONSs and other nurses (see Chapters Eleven & Twelve). This section of the chapter discusses how these relationship types add to our understanding about relationships among groups of nurses, in two ways. Firstly, it adds to the existing nursing literature on relationships between specialist and community nurses. Secondly, it opens a debate on the relationships between specialist and hospital-based nurses.
Community Nurses and CNSs

Previous studies in the nursing literature have examined relationships between CNSs and DNs; they have overlooked the relationships which develop between CNSs and HVs. These studies have suggested that relationships are influenced by the degree of hands-on nursing care provided by CNSs and by the specialty to which CNSs are affiliated (Chapter Four). It is generally agreed that when CNSs work in specialities which are unfamiliar to DNs, DNs benefit from CNS posts (Haste & MacDonald 1992, Layzell & McCarthy 1993, Griffiths & Luker 1994b, Hunt 1996). However, there has been little agreement amongst community nurses as to how much hands-on nursing care should be delivered by CNSs (Haste & MacDonald 1992).

This study suggests that neither areas of work which are unfamiliar to community nurses nor the amount of hands-on nursing care provided by CNSs, satisfactorily explains the nature of relationships between DNs and CNSs. How CNSs work within their specialty and whether or not nursing care of patients is planned between CNSs and community nurses is of the greatest importance. When ‘Partnership’ is developed between POONSs and DNs some hands-on care is retained by POONSs. This differs from ‘Empowerment’ where much of the hands-on nursing care is given over to DNs. The levels of hands-on care provided by DNs therefore differs between the two types of relationship. However, in both relationship types, hands-on care is planned between DNs and POONSs resulting, for DNs, in high levels of satisfactory working relationships. Where DNs’ participation in hands-on care is limited and uncoordinated, disempowerment occurs (see Chapter Eleven). For some PHCT members, being disempowered from providing care in highly specialised areas, such as childhood malignancy, is seen as an acceptable method of work. However for most, it is not. DNs who developed ‘Disempowerment’ relationships with POONSs expressed low levels of satisfaction in their professional relationships with POONSs (Chapter Eleven). One way in which this situation could be remedied is for all POONSs to collaborate with DNs, planning hands-on care in a manner which exists in both ‘Partnership’ and ‘Empowerment’.
Better communication has previously been reported as a solution to improving relationships between community nurses and CNSs (Haste & MacDonald 1992, Williams 1993). In this study communication between POONSs and community nurses has been a key factor in determining the types of relationship developed between POONSs and community nurses. 'Disempowerment' in which poor communication is a key feature, does much to support the recommendations of previous authors, for better communication between CNSs and community nurses.

An additional solution to enhancing relationships between CNSs and DNs lies in community nurse training of CNSs (Kitson et al. 1987, Wade & Moyer 1989, Williams 1993). Most staff at regional hospitals considered community nurse training augmented the relationships between POONSs and community nursing staff (see Chapter Ten). However, community nurses themselves were divided in their opinions - several felt strongly that CNSs should acquire community nursing experience, but most believed this unnecessary for POONSs. It is probable that community nurses formulate these beliefs around their own shortfalls in knowledge - the more specialised the field of practice, the less DNs perceive the necessity for CNSs to possess community nursing qualifications. Thus the supposition made by previous authors - that community nurse training by CNSs enhances the relationships between CNSs and DNs - is not supported by this study.

The types of relationships formed between POONSs and DNs have been influenced by the mixed funding sources of POONSs. These influences have also affected the relationships which develop between POONSs and HVs. This research suggests that the strategies adopted by the two main charities do little to enhance the relationships between POONSs and HVs. The empowering nature of CRMF ensures that HVs gain decision-making abilities from POONSs. However in this study there was limited evidence of MPNs establishing and maintaining relationships with HVs. The reason for this is uncertain; whether the heavy work load of terminally ill children (where the HV's role is ill-defined) hindered relationships between MPNs and HVs or whether there was a dearth of pre school age children with cancer impeding interviews with HVs is unknown. However, the emphasis placed upon terminal care
and bereavement work by CRMF, ensures that this type of work takes precedence over other types. Therefore it is possible that the strategy adopted by CRMF, to prioritize the terminally ill and the bereaved, resulted in limited communication between MPNs and HVs.

Similarly, the philosophies of CLIC hampered relationships between HVs and POONSs. The all encompassing nature of CLIC nurses’ work meant that HVs had limited contact with POONSs and were more generally called upon only in crisis situations. These approaches do little to engender professional relationships between groups of nurses. In contrast, where POONS services are funded by organisations which are professionally directed, HVs developed very different and sustaining ‘Partnership’ relationships with POONSs. Hence, although it is acknowledged that individual personalities affect relationships, this research suggests that the variation in sources of funding does much to either impede or encourage the relationships which develop between CNSs and community nurses.

Hospital-based Nurses and CNSs

Relationships between groups of hospital-based nurses have hitherto been overlooked in both the nursing and sociology literature. This study has consequently opened a debate in this area. Drawing on both data from this study and on studies examining relationships between doctors and nurses, conclusions about the relationships between hospital-based nurses and specialist nurses can be drawn.

Relationships between doctors and nurses have been defined in terms of differing territorial space, with the nurses’ working world being the ward, whilst the doctors’ is the hospital, and when absent from the ward doctors are perceived by nurses not to be working (Mackay 1993). Applying the analogy of territorial space to POONSs, their working worlds extend beyond the confines of the hospitals’ boundaries. The work of POONSs takes them to OPDs, other hospitals and patients’ homes, as well as to wards. Although there was no evidence from the data to suggest that SNs consider that POONSs are not working whilst absent from wards, distance exists between POONSs and junior nurses in ‘Independent Reciprocity’. This is exacerbated
when SNs have limited responsibilities for or prior knowledge of the children visited by POONSs. Different territorial space may therefore be one explanation for this type of partnership between POONSs and SNs.

Regardless of work location and the funding bodies with which POONSs are associated, sisters in this study developed closer relationships with POONSs than SNs. One explanation for this lies in their shared decision-making responsibilities and stresses, which go hand-in-hand with seniority. Although the decisions, responsibilities and stresses of sisters and POONSs differ (particularly at DGHs where sisters have limited custody of children with malignant disease), carrying office enhanced their relationships. A contribution which this research therefore makes to understanding the relationships between sisters and specialist nurses, lies in highlighting these shared work components. It is argued that sharing decision-making responsibilities and stresses create close relationships between sisters and specialist nurses and, although mixed funding sources affect the types of relationships which develop between sisters and specialist nurses, they do not impinge on this closeness.

Further contributions this study makes towards understanding relationships between hospital-based and specialist nurses concerns deskilling. Deskilling of nurses has previously been reported as a potential area of concern when CNSs provide high levels of hands-on care (RCN 1988, Wade & Moyer 1989, Nash 1990, Williams 1993). Findings from this study suggest these concerns to be substantiated through ‘Relinquishment’ and deskilling of junior doctors has earlier been ascribed to this type of partnership. Deskilling occurs because junior SNs at DGHs are rarely provided with opportunities to give nursing care to children with malignant disease (see Chapter Twelve). Not only are small numbers of children with malignant disease referred to DGHs but when they are, POONSs who adopt a ‘Relinquishment’ approach provide this nursing care in preference to junior nurses. Hence, the potential for deskilling arises. One solution to overcoming this problem lies in basing all POONS services at regional centres. A network of ‘named’, ‘link’ nurses located at DGHs could then be developed to liaise closely with regional POONSs (South Thames Paediatric Oncology Working Party 1996). This would maintain the close
links currently enjoyed between regional centres and DGHs where CLIC nurses operate and reduce the reliance upon one named person i.e. a district-based POONS, to provide care. Whilst maintaining good links between the two hospitals, this would increase hospital-based nurses’ contacts with children with cancer and hand back to them skills which are normally associated with hospital-based nurses.

In addition to the mixed funding sources of POONSs, systems of nursing work affect the relationships between POONSs and SNs. In this study the three systems of work which influence relationships between POONSs and SNs are primary nursing, twelve hours shifts and permanent night duty. Primary nursing has enhanced close ‘Integrated’ relationships between POONSs and SNs, whilst twelve hour shifts have contributed towards ‘Independent’ relationships and permanent night duty towards ‘Relinquishment’. This suggests that no matter what attempts may be made by POONSs to establish ‘Integrated Reciprocity’ with SNs, there may be organisational forces beyond the control of POONSs which hinder such attempts. Two such determinants are twelve hour shifts and permanent night duty.

In summary, this research has opened a debate on relationships between hospital-based and specialist nurses. In so doing, it has suggested firstly that mixed funding sources affect the type of relationships developed between the two groups of nurses. Secondly, it has charged that there are other forces at play which are independent of these influences. These include the bonds which develop between all senior nursing staff (i.e. sisters and CNSs) who share responsibilities and decision-making powers and external factors such as primary nursing, twelve hour shifts and night duty, which affect the relationships between specialist nurses and SNs.

‘Partnership’ and ‘Empowerment’

The concepts of ‘empowerment’ and ‘partnership’ currently hold much favour both politically and professionally and much lip service is paid to these ideals. ‘Partnership’ in particular, between professionals, is seen as a method of work to be aspired to (e.g. DoH 1993b, DoH 1994, Dorrell 1995, Dorrell 1996, NHSME 1996, DoH 1996b). However, ‘partnership’ and ‘empowerment’ are frequently intertwined
lacking clear definition and have hitherto been treated as concepts which do not need contextualising. Furthermore, to date, there is a dearth of research which explores the two concepts (see Chapter Four). Taking relationships with POONSs as an example, this research suggests firstly that both ‘empowerment’ and ‘partnership’ are complex and require contextualising in order to understand their development. Secondly, this study suggests that there are elements of empowerment and partnership which are difficult to disentwine. However, each concept does have distinctive characteristics. Finally, it contends that ‘empowerment’ occurs amongst professionals, not just between professionals and their client groups.

‘Empowerment’
In spite of sharing some common characteristics, this study suggests that there are features of ‘empowerment’ which are distinct from ‘partnership’. In the main, these concern giving power to those who lack it (Gibson 1991 & 1995, Breton 1994a & 1994b, Deveaux 1994, Wallack 1994, Darbyshire & Morrison 1995). Empowerment arises when patients with rare disorders have specialist needs which some groups of health care professionals lack the specialised knowledge to provide. The example used in this study concerns childhood cancer and the lack of specialist knowledge possessed by PHCTs. Here, power may be transferred from POONSs to PHCTs (more particularly DNs) during a child’s terminal illness. This occurs when POONSs teach PHCTs to undertake specialist tasks with which they were previously unfamiliar and are readily available to answer their queries. This, in turn, enables PHCTs to make treatment-related decisions. This is distinct from ‘partnership’ where much of the power (i.e. specialist skills) is retained by professionals, in this instance, POONSs.

This study has not only shed light on how empowerment between groups of health care professionals is achieved but also suggests that a mixed economy of health care influences whether or not empowerment of health care professionals occurs. The divergent strategies of the two main charities associated with the work of POONSs influences the likelihood of empowerment of PHCTs. In this study, ‘empowerment’ is best observed in MPNs; an empowering strategy is adopted by CRMF and is a stipulation of funding POONS services.
'Partnership'

'Partnership' is a term which may be applied to a number of relationships between health care professionals, suggesting that it is a complex phenomena which demands contextualizing. At one level, 'partnership' is consciously constructed between health care professionals. Here, 'partnership' evolves over time between individuals or groups who collaborate in relation to a specific incident - in this example, to care for a child with malignant disease and his/her family - where professionals are not previously acquainted. In this example, 'partnership' occurs as one of three alternative types of relationship between POONSs and PHCTs. This arises because POONSs establish rapport with PHCTs at an early stage of a child's cancer 'journey', building a partnership over time. 'Partnerships' of this type are then maintained through continually exchanging information about patients and their families and are established even if PHCTs do not have an immediate role in a family's care. On a second level, 'partnership' may be inherent. This arises when individuals or professional groups are familiar with each other, working in the same environment, with similar groups of patients. In this situation, 'partnership' is complex and develops in very different ways. In this study a partnership typology between POONSs and other hospital-based health care professionals has been developed comprising four types of 'partnership'. The types of partnership are influenced by local and traditional cultures, individual personalities of both POONSs and their colleagues, hierarchy and by the mixed economy of care.

Entwining 'Partnership' and 'Empowerment'

Both 'partnership' and 'empowerment' imply collaboration between individuals or groups of individuals (see Chapter Four). It is this collaboration which creates difficulties distinguishing between 'partnership' and 'empowerment'. These difficulties are exemplified in this study in the Mixed 'Partnership/Empowerment' type of relationship (see Chapter Eleven). This type of relationship arose from characteristics common to both 'Empowerment' and 'Partnership' relationships. Adopting a planned approach to discharging terminally ill children home from hospital, establishing face-to-face contact with PHCTs during this period, and facilitating access of patients to DNs were practices of POONSs which featured in both relationship types, producing
Mixed ‘Partnership/Empowerment’. These features, and this type of relationship in particular suggest that there are difficulties in unravelling the two concepts.

Implications for Practice and Policy (1): Families
From this study, a number of conclusions for both nursing practice and policy can be drawn which have implications for families caring for children with malignant disease in particular, and for families with chronically sick children in general. This research did not set out to examine the relationships between POONSs and the families with whom they work. However, the different ways in which nursing care is provided by POONSs and the influences funding organisations have on professional relationships, enable some conclusions to be drawn.

Parents have expressed the need for POONS posts through their involvement in establishing services. Advantages to families of POONS services have been demonstrated through the experiences of those who have benefitted from their support, compared to those who have not (Bignold et al. 1994a). Although it has previously been determined that families benefit from the services of POONSs it is not possible to know whether parents prefer a service in which a ‘hands-on’ type of nursing care is provided, or they favour a ‘hands-off’ approach, or a mixture of both. However studies such as those by Darbyshire (1994) and Gibson (1995) suggest that parents have valued the support given by professionals which has enabled them to provide their child’s care. Such studies lead the author to suggest that a model in which POONSs predominantly practice a ‘hands-on’ type of care, such as provided within the CLIC model, may restrict the degree to which parents become empowered. It may also inhibit the process of ‘normalisation’ in which families struggle to return to a normal family life following a child’s diagnosis (Faulkner et al. 1995).

The intention of today’s market-driven economy is that consumers of health care (i.e. patients) should benefit from the choice which arises when a range of services are offered (DoH 1989a). This study has demonstrated that the variety of services offered by POONSs to families varies according to where they live, where their child is subsequently treated and who funds the POONS service provided within their locality,
rather than through parental choice. Two examples which illustrate the influences of
the different funding sources relate to the care provided to families at diagnosis and
bereavement. Since the time of diagnosis can be one of great uncertainty and
returning home for the first time can be isolating (e.g. Lansdown & Goldman 1988,
Bignold et al. 1994a, Faulkner et al. 1995, Sloper 1996), it follows that families will
derive benefit from the support of POONSs at this time. The variety of services
offered by POONSs across the three ‘Funder’ models, suggests this support is, in
part, determined by the strategies of the charities funding POONS posts rather than
by the needs of newly diagnosed children and their families. Bereavement services
offered by POONSs similarly reflect the strategies of charities funding POONSs and
not parental requirements (see Chapter Six).

POONSs’ relationships with other health care professionals also have indirect
implications for families. The results of this study suggest that when PHCTs are
‘disempowered’, families long-term relationships with PHCTs may be damaged. The
roles of PHCTs are ill-defined in ‘Disempowerment’ and poor communication
compounds this problem (see Chapter Eleven). This is not only detrimental to PHCTs
but may also undermine families’ relationships with PHCTs. Examples of this have
been demonstrated in the poor relationships which DNs develop with families in
‘Disempowerment’ (see Chapter Eleven). In extreme cases when GPs are excluded
from care, families register with alternative GP practices following the death of their
child.

A mixed economy of health care also has implications for other sick children and
their families in some circumstances. The two-tier services which exist in several
local areas in which POONSs operate mean that the needs of families caring for a
sick child at home with a disease other than cancer, may be unmet. In some instances
this has resulted in hospital-based health professionals witnessing resentment between
parents when children with cancer received services which other chronically ill
children were denied. This is particularly evident in areas where the establishment of
CLIC nursing services have historically hindered the development of PCN services.
Since the choice of the type of POONS service is restricted to families according to the area in which they live and the centre to which their child is referred, one solution to the diversity of services provided to families, would be to base all POONS services at regional centres. This would ensure that children not only receive standardised medical treatment, through the collaboration of UKCCSG centres, but would also ensure that comparable services were offered to families by POONSs, regardless of their geographical location. To diversify patient choices within a regional POONS service, further development of PCN teams might offer families both a locally-based generic service and a regionally-based specialist, knowledgeable in childhood cancer. This would ensure flexibility for families to choose how much support and hands-on care to accept locally, from appropriately trained paediatric nurses. It would also ensure that PCNs and families alike could draw on the expertise of a regional POONS. In such environments all families within a locality would receive paediatric nursing support at home, not just those families whose children have cancer. It would also be consistent with national policy in offering more choice to patients at a local level (DoH 1989a) and would contribute to 'good practice' (DoH 1996a). Furthermore, at a macro level, this model of care could be adopted by other paediatric specialties where primary, secondary and tertiary care is provided.

Implications for Practice and Policy (2): Managers, Health Economists and Policy Makers

Findings from this study also have implications for managers, health economists and policy makers. Firstly, there are implications relating to the high cost of district-based POONSs. Clinical nurse specialists are regarded as highly qualified and experienced nurses (RCN 1988) who, by the nature of their grades, command high salaries. In hospitals where a number of CNSs may be employed, the salary costs to hospital Trusts can be considerable (for example see Arnfield 1996). At DGHs where POONSs are employed to provide care to very small numbers of patients, their services are invariably more expensive than those at regional centres. The cost of POONS services is particularly pertinent for DGHs not only because of the small numbers of children they cater for but also because the highest grade (grade '1'), and therefore the most expensive POONS service, was found within the CLIC model.
Secondly, there are implications because of the precarious nature of charity funding. CLIC nurses have been funded *ad infinitum* whilst other POONSs have been 'pump primed' (Chapter Three). Consequently, there is the potential for such funding to place unexpected financial burdens on the clinical directorates supporting them. This has already been demonstrated through the collapse of the Rupert Foundation when replacement funds had to be rapidly located by employing authorities (Chapter Three). Recent financial difficulties reported within CLIC (Trump 1996) must surely raise concerns not only amongst CLIC nurses but also amongst managers. In a climate of cost efficiency a local hospital Trust may not be prepared to take over the expense of a CNS service which provides care for such small numbers of children.

The small numbers of children referred to DGHs ensure that teams of POONSs would be prohibitively expensive and so working single-handedly is common amongst district-based POONSs (see Chapter Six). Both 'Relinquishment' and 'Disempowerment' lean towards an approach which suggests that single-handed POONSs are somewhat isolated from other colleagues. The 'extreme emotional challenge' posed by caring for dying children (Chapter Two) must inevitably raise concern amongst managers for the well-being of single-handed POONSs, particularly for those who provide on-call services to all families, regardless of a child's disease status, 24 hours a day, seven days a week, 365 days a year. The suggestion of enhancing the development of locally based generic PCN teams to work alongside regionally based teams of POONSs would be one solution to this problem.

When POONSs work independently of junior hospital-based health professionals, there is the potential for duplicating work, which also has cost implications. An example of such potential was illustrated by junior doctors at the Northern City Children's Hospital - due to their lack of insight into MPN services within their hospital, SHOs believed that MPNs only provided services to terminally ill children and their families. Senior staff, with a greater understanding of their work talked of the important role MPNs played in facilitating shared care between Northern City and DGHs who referred children to the unit. Consequently whilst one SHO talked of the amount of time she spent liaising with local hospitals prior to a child's first discharge.
from Northern City Hospital, senior medical and nursing staff commented that POONSs did the same. Such potential for repetition inevitably has cost implications if two different health care professionals provide the same service. One solution to this situation lies in implementing an induction programme for all new SHOs at regional centres. This not only benefitted SHOs who developed an ‘Integrated Reciprocity’ type of partnership with POONSs (see Chapter Twelve) but could also limit the potential for repeating tasks undertaken by others, thereby reducing costs.

When POONSs are perceived to be experts by those who they work with, junior staff have much to learn from POONSs. This is of particular benefit to SHOs who are required through the Calman Report (DoH 1993a) to participate in training programmes during their experiences as junior doctors, and assists junior nurses through their journey towards becoming an ‘expert practitioner’ (Benner 1984). Teaching not only benefits junior staff but policy makers and managers also profit. When POONSs teach junior doctors, it is invariably cheaper than if their more expensive senior medical colleagues were to undertake this task.

**Recent Developments in Funding Arrangements**

In a rapidly changing NHS, there have been many changes affecting POONS services since the outset of this study. Most particularly the philosophies of several charities funding POONS posts, including the two main charities with whom they are associated, have been redefined and strategic boundaries extended. Whilst CLIC expanded its remit in 1994 to fund posts at regional centres throughout the UK and internationally, CRMF are establishing MPN posts at DGHs. This has been demonstrated by recent job advertisements for MPNs at Whittington Hall Hospital, Chesterfield; Havering Hospitals NHS Trust, Romford, Essex; Northallerton, North Yorkshire and the Garden House Children’s Hospital within The Royal London Hospital (Nursing Times 1996). Another charity LATCH, also more commonly associated with funding regionally-based posts, have provided funds to establish a district-based POONS at West Wales General Hospital (Nursing Times, August 16th 1996). Other new district-based posts are also developing with funds from locally established charities (Nursing Times 1997).
The expansion of district-based posts has resulted in charities competing to fund new posts and the author is aware that this has led in one region, to the establishment of several POONS services both at the regional centre and in DGHs within the same region. This has resulted in POONSs competing with each other to provide different types of POONS services to the same groups of children. The author is also aware of a recently established CLIC-funded post at a DGH which was set up in an area where regional POONS services had successfully existed for ten years. The necessity for such a service was not fully considered prior to the instigation of this service and the district-based POONS service was soon abandoned.

**Conclusions for the Future**

The strategies adopted by the charities funding POONS posts have been responsible for the emergence of three ‘Funder’ models associated with the work of POONSs and for different types of relationships between POONSs and other health care professionals. It is unlikely that POONSs funded by CLIC, employed at regional centres, provide the same level of hospital-based hands-on nursing care as the CLIC nurses at DGHs in this study, since the skills required to provide this care would be acquired by the nursing staff on the ward. Equally, with the small numbers of children with malignancy within any one district, it is improbable that district-based MPNs retain the knowledge or command the caseloads to necessitate empowering PHCTs. Therefore, the recent emergence of regionally-funded CLIC nurses and district-funded MPNs would support developing two models for the future: a CLIC-type model associated with services provided by DGHs and a Macmillan-type model affiliated to regionally-based services. Different models of POONSs and various relationship types described in this study have been affiliated to the philosophies of the two main charities funding POONS posts. With changing charities’ boundaries the structure, organisation, clinical practices and the relationships which POONSs form, are invariably changing. Future studies would need to take these changing patterns into account.
The change in government during 1997 is unlikely to have any impact on alleviating the huge financial demands which health care places on the welfare state. The New Labour government have pledged to examine a variety of funding sources to alleviate this ongoing financial burden. This being so, it is unlikely that the mixed economy of health care, and the partnerships developed between the public and the voluntary sector will diminish in the future. Thus, areas of health care which appeal to the general public, such as childhood malignancy, may continue to attract large sums of voluntary sector funding. In such specialties, with the increasing costs of health care to the public purse, it is probable that voluntary sector funding will continue to be relied upon as a source of health sector funding.

Health care reform during the 1990s has resulted in a decrease in the overall number of nursing staff, downgrading of clinical nursing posts, locally negotiated pay awards and the emergence of fixed term contracts. Such moves have created uncertain futures for nurses regarding job security, compared to the past. The instability of POONS posts which has arisen from their charitable funding status, inevitably compounds this precariousness. This creates an even more unstable future for health care professionals funded by charitable sources, than for their peers financed centrally from NHS sources. These concerns may also affect other public sector workers funded by the voluntary sector and may continue to cause unease if voluntary sector funding continues to be relied upon.

The theoretical conclusions to be drawn from this research and the implications both for policy and practice, lead the author to suggest that all POONSs should be located at regional centres, rather than DGHs. However, as observed in recent moves towards increasing the number of district-based POONSs, this is unlikely to occur in the immediate future. Since the publication of the Hunt Report (Hunt 1996) however, discussions are beginning to emerge between the charities, the professional bodies (PONF and the UKCCSG) and amongst POONSs themselves. Such discussions have implications for the future of POONSs services which may limit the further development of district-based POONS services. Furthermore, with recent drives towards the Diana Princess of Wales Memorial Fund filling the current gaps in PCN
services (Burr 1997), there are encouraging moves afoot to remedy some of the discrepancies in services highlighted in this study - not only for children with cancer and their families but for all sick children being cared for in the community.
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APPENDICES
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<td>Hospital for Sick Children</td>
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| Telephone No. |
2nd September 1994

Dear Clinical Director

Re: Paediatric Oncology Community Nurse Specialists - Towards a Model of Good Practice

You may be aware that the Royal College of Nursing and the United Kingdom Childrens Cancer Study Group (UKCCSG) are collaborating to jointly undertake the above research, funded by the Department of Health.

The first stage of this work involved interviews with all nurse specialists currently working in the field as paediatric oncology community nurse specialists (POCNS). A summary of which is enclosed with this letter. The second stage is to examine the working relationships between POCNS and those professionals with whom they work closely, in 3 centres.

All of the participating nurse specialists are aware of the continuing work involved in this project.

I hope that you will be happy for me to conduct interviews with several members of the multidisciplinary team within your unit who are involved in working with ........... This will include members of the medical staff, nurses and social workers.

I shall be glad to make contact with the staff myself to arrange the interviews at times and places convenient to the participants. If you would like any further information please do let me know.

Yours sincerely

Jane Hunt RGN RSCN DN
Nurse Researcher

Appendix 2
WORK STRUCTURE

1. What is the title of your job?

2. What date was your service set up? [ ] [ ] [ ]
   month year

3. How long have you been in post? [ ] [ ] [ ]
   years months

4. If you have not been in post since the outset of your service, were you employed to expand the service or replace a previous employee?

5. If you have replaced a previous employee can you say why he/she left their job?

6. Do you work in isolation or with another like specialist nurse? If with another like specialist nurse/s:
   (a) is there a hierarchical structure within?
   (b) how do you organise your shared workload?

7. Which other member/s of the multi-disciplinary team do you consider you work most closely with?

Appendix 3
8. Are you based at:
   (a) Regional U.K.C.C.S.G. centre
   (b) Paediatric department at a local D.G.H.
   (c) Other (please specify)

CASELOAD

9. Do you care solely for children with cancer or leukaemia?
   If no: (a) What other medical conditions do you see?
   (b) (i) Has your service always offered this support to other groups of patients?
   (ii) If not always, how long ago was this part of the service introduced? [ ] [ ] [ ] [ ]
             years months
   (c) What percentage of your time is spent with these other children?

10. Do you routinely carry out home visits?

During the last month:

11. How many children did you have in your care?

12. How many newly diagnosed cancer/leukaemic children have been placed in your care?

13. How many newly diagnosed cancer/leukaemic patients have you seen in your hospital?
   If appropriate, at what stage of the children’s disease did you make contact with them and/or their families?
14. How many of these children have you visited or will you be visiting: (a) at home (b) elsewhere

If none, do you offer such a service?
If appropriate, what was the main purpose of these visits?

15. How many terminally ill children have been in your care?

16. How many home visits have you made to these children?
If applicable: for how long, on average were you with the patients?
Can you describe the nature of these visits?

17. (a) Have you been 'phoned/bleeped or made any calls out of hours?
(b) Have you been visiting out of hours?

If yes to either of the above: Can you say why?
How does this service operate?
If no to either (a) or (b): do you offer an out of hours service?

18. How many "hands-on" nursing tasks have you performed:
(a) In the patients’ homes
(b) In your hospital
(c) Another location (please specify)

If performed, what did these consist of?

19. How many children have you visited at home who are disease-free and not receiving treatment?
20. How many bereaved families have you visited?
   Can you briefly describe your bereavement service?

21. How many funerals have you attended?

22. Have you had any contact with any of the following professionals, either visiting or by telephone:

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23. Have you visited anyone else in the last month not already listed?
   If yes, who and why?

24. How many miles have you clocked up?
25. Would you say that it has been an average month for you?
   **If no:** has it been busier or quieter than usual?
   was there anything specific that made this an unusual month?

26. Is your patient referral area:
   (a) Regional
   (b) District
   (c) Other (please specify)

27. Approximately how far away from your base does your furthest patient live?

28. Are you able to provide an equivalent service to your furthest patient to one living locally?

**DRUG ADMINISTRATION**

29. Do you routinely deliver individually prescribed drugs to patients' homes?
   **If yes,** which drugs do you most commonly deliver?

30. Do you carry stock drugs which may be administered when required?
   **If yes,** which drugs do you routinely carry?

31. Do you carry controlled drugs?
   **If yes,** are any special provisions made for their transportation?
32. Do you administer chemotherapy in the patients' homes?  
   If yes, please specify

33. Do you administer any other drugs?

RESPONSIBILITIES AND MANAGEMENT

34. Does your job involve any of the following components: 
   (a) Managing other nurses 
   (b) Administrative duties relating to your funding body 
   (c) Teaching (not parents) 
   (d) Clinic input 
   (e) Giving advise to other patients not related to your caseload 
   (f) Other (please specify)  
   If yes to any of the above please state which and what percentage of your time is taken up with each component and describe these responsibilities.

35. Do you work full or part-time?  
   If part-time, how many hours per week do you work?

36. What grade are you?

37. Have you always been this grade in this job?  
   If no: what were you previously?  
   what influenced this change?

38. Who funds your (a) salary  
   (b) expenses
39. Has this job always been funded from these sources?  
   **If no**, who previously funded this post?  

40. Will your present funding continue *ad infinitum*?  
   **If no**, what do you expect will happen?  

41. To whom are you managerially accountable?  

42. To whom are you professionally accountable?  

43. Do you wear a uniform?  
   (a) **If no**, (i) Are there any restrictions put upon you in what you can wear?  
      (ii) Do you put restrictions on yourself?  
   (b) **Whether you wear a uniform or not**, are you happy with this arrangement?  

44. Do you have:  
   (a) own office  
      **If no**, do you share an office?  
      **If you share an office**, who do you share with?  
   (b) phone  
   (c) answerphone  
   (d) pager/hospital bleep  
   (e) mobile phone  
   (f) secretarial support  
   (g) **If secretarial support available**, how does this work?
DOCUMENTATION

45. What sort of information do you document about your patients?

46. Where do you document this information?

47. Do other members of staff have access to these records?

48. Do you record how you spend your day?
   If yes, how or where do you record this?

PERSONAL DETAILS

49. Please list your professional qualifications.

50. Are there any qualifications which you do not possess that you feel would benefit your job?

51. What opportunities are open to you for further training?

52. What was your job prior to this?

53. What other relevant previous experience do you have?

54. How old are you?
   1. [ ] 20-24   2. [ ] 25-29   3. [ ] 30-34
   4. [ ] 35-39   5. [ ] 40-44   6. [ ] 45-49
   7. [ ] 50-54   8. [ ] 55-59   9. [ ] 60-65
**SUPPORT**

55. Have you had any children?  
   **If yes,** do they live with you?

56. Do you live with anyone else?

57. Do you have any other dependents not already mentioned who make demands upon your time?  
   **If yes,** can you say who?

58. Under what circumstances do you feel you need emotional support in relation to your job?

59. Do you get this support?  
   **If yes,** from whom?

60. Can you say what the good parts of your job are?

61. What are not so good?

62. Is there anything which has not been covered which you feel you would like to comment on?
Aide Memoire - SENIOR NURSING STAFF

I am looking at the role of the paediatric oncology community nurse specialist and more particularly how they work with medical and nursing staff, both within the community and the hospital setting. I'd like to investigate how you see the role/s of .............. . As a senior member/s of the nursing staff you have probably worked with her/them for some time.

1. I wonder if you could start off by telling me something of your earliest contacts with ..........., how you envisaged their roles to be, whether that has changed with time and perhaps the sorts of situations that you now have contact with them.

PROMPT - Involvement in setting up service.
Levels/reasons for contact
Impact on own role/job
Interprofessional relationships
Threat to own job/teaching/replacing

2. What do you see as her/their main functions?

PROMPT - Community/Ward/Clinic
Relationships with families/time availability
Education/Task oriented
Comparison with own areas of responsibility/differences with own role
Professional autonomy
Relationship with other nursing staff
Relationships with medical staff/different from own

3. Do you see her/their educational/professional backgrounds differing from your own?

PROMPT - Knowledge levels
Previous experience
Professional training

4. Some community paediatric oncology nurse specialists in this field feel that further training opportunities, studying or courses are limited to them due to 'caseload' commitments, in other words responsibility for their own patients, coupled with getting cover whilst they’re away makes studying difficult. What do you feel about this?

PROMPT - Professional autonomy/professional rivalry
Funding/time availability
Own training needs/POCNSs training needs

Appendix 4
5. You are probably aware of the charitable input to many of these such nursing posts, is this an issue that you have ever thought about in relation to your own job?

PROMPT - Job security/insecurity
   Grading
   Funding for things they are not able to do
   Different models of care

6. Do you see this as the sort of job that you would like, if so what might you find appealing or unappealing about it?

PROMPT - Relationships with families
   Relationships with other professionals
   Areas of stress
   Role perception development

PROMPT - Areas of stress