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Exploring Complexity in Community Palliative
Care: A Practitioner Based Approach to Research
and Development

By

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A thesis submitted to satisfy the requirements for the degree of
Doctor of Philosophy in Primary Health Care Studies

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Authors Declaration

The research for this thesis was conceived and designed by the author. All literature reviews and methodological work are the sole work of the author. The research in Chapter 5: 'A multi-method study into the reason for admission of palliative care patients into hospital beds' was conducted by the author alone. The research presented in Chapter 6: 'Health care assistants in community palliative care: invisible workers, emotional labourers' was a collaborative project. The overall study was designed by the author; the interview schedule was developed collaboratively by the author and his 'co-action researchers'. The field work interviews were conducted by Dr Kashifa Mahmood and Elizabeth Pitt. Analysis and presentation of the results is the work of the author alone.

No part of this thesis has been previously submitted for a degree at this or any another university.

Abstract

This thesis explores the complex discipline of community palliative care. Palliative patients suffer from a range of conditions, have complex, evolving clinical problems and receive care from a wide variety of health and social care professionals. Understanding these issues is central to effective service provision and maintaining continuity of care for patients and their carers. Current community palliative care provision in the UK is the result of the co-evolution of the emergent specialties of palliative and primary care over the past sixty years. A critical realist and practitioner based research approach is used in a multi-method study of the reasons for emergency admission of palliative patients into hospital and a qualitative study exploring the work and experiences of health care assistants providing practical supportive care for palliative patients in their homes. Examining narratives of patients, carers and health professionals enables in depth exploration of the fundamental elements and contexts which define the inherent complexity of this area. Emergency admission of palliative patients represents a significant breach in continuity of care often resulting in disruption for both patient and health care services. The reasons for these admissions are many and complex. Relationships of power between different health professionals and between patients and health professionals exert a major influence on community palliative care provision and the process of admission. Health care assistants are relatively powerless and employed as basic carers, yet in community palliative care they undertake emotional labour, for which they draw on their personal resources. This aspect of their practice is crucial for patients and their carers; however it is largely unrecognised by formal health care services. Undertaking research in the context of a community palliative care team enables the development of a community of research practice. This provides an effective model for both developing an evidence base for community palliative care and the development of appropriate local services.

Abbreviations

A/E	Accident and Emergency Department
APM	Association of Palliative Medicine
CARN	Collaborative Action Research Network
CNS	Clinical Nurse Specialist
COPD	Chronic Obstructive Pulmonary Disease
COREC	Central Office of Research Ethics Committees
CPCT	Community Palliative Care Team
CR	Critical Realism
DH	Department of Health
EAPC	European Association for Palliative Care
EAU	Emergency Admissions Unit
EBM	Evidence Based Medicine
EBP	Evidence Based Practice
EI	Emotional Intelligence
EoLCP	End of Life Care Programme
FSS	Family Support Service
GP	General Practitioner
GPR	GP Registrar
GSF	Gold Standards Framework for Palliative Care
HA	Health Authority
HCA	Health Care Assistant
HCP	Health Care Professional
HCF	Home Care Facilitator
ICS	Intermediate Care Service
LCP	Liverpool Care of the Dying Pathway
LREC	Local Research Ethics Committee
MCCC	Marie Curie Cancer Care
MCR/MCS	Macmillan Cancer Relief/Support
MRCGP	Member of the Royal College of General Practitioners
MOH	Medical Officer of Health
NA	Nursing Auxiliary

NCPC	National Council for Palliative Care
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NIH	National Institute for Health
NSF	National Service Framework
NSCR	National Society for Cancer Relief [Now Macmillan Cancer Support (MCS)]
OT	Occupational Therapist
PCG	Primary Care Group
PCT	Primary Care Trust
PHCT	Primary Health Care Team
POS	Palliative Outcome Score
PPOC	Preferred Place of Care Tool
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCP	Royal College of Physicians
RF	Research Fellow
RSM	Royal Society of Medicine
SHO	Senior House Officer
SPR	Specialist Registrar
SW	Support Worker
UK	United Kingdom
WHO	World Health Organisation

Chapter 1 - Introduction: continuity and complexity in community palliative care

1.1 Introduction

This thesis explores the research which I have undertaken in collaboration with members of the Community Palliative Care Team (CPCT) in which I work. The research has been grounded in the practical consideration of developing an effective and responsive palliative care services whilst generating an evidence base for community palliative care in the UK. I started undertaking research for this thesis whilst a specialist registrar in the locality and continued when appointed as a community based consultant in palliative medicine in 2002. Over a period of 4 years we have been developing a 'community of research practice' within the clinical team, undertaking research to inform the development of palliative care and developing new research questions.

In this introductory chapter I will present the background to the research undertaken: the definitions of palliative care I have used, the socio-geographical context of the research and the complexity involved in delivering community palliative care from the perspective of maintaining continuity. I will briefly describe complexity theory as a tool for understanding the complex world of palliative care, describing its emergence in my own thinking, since this has shaped the methodological approach I have adopted in the research. Finally, I will present a brief overview of the subsequent chapters and the two themes which run throughout the thesis; an empirical and a methodological theme.

1.2 Definitions

I will use the term 'palliative care' as recently defined by Randall and Downie (2006) in their book 'The philosophy of palliative care':

'Palliative care is the care of patients whose disease is incurable and is expected to cause death within the foreseeable future' p224.

Definitions of palliative care as a holistic patient centred specialty have emerged over the last 20 years and those in current usage are given in Box 1-1.

‘Palliative care is the active holistic care of patients with advanced, progressive illness.

Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments’ p20 (NICE, 2004).

‘Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications’ p84 (WHO, 2002).

‘Supportive care helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.’ www.ncpc.org.uk/palliative_care.htm (Accessed 22/09/06).

‘Terminal care is an important part of palliative care and usually refers to the management of patients during their last few days or weeks or months of life from a point at which it becomes clear that the patient is in a progressive state of terminal decline’ p5 (NCPC, 1995).

‘There is no exact definition of **end of life**; however, the evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death. Older age and frailty may be surrogates for life-threatening illness and co-morbidity; however, there is insufficient evidence for understanding these variables as components of end of life’

<http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm> (Accessed 22/09/06).

Box 1-1- Definitions of palliative care

Confusion can arise because four overlapping terms are currently used: palliative care, supportive care, terminal care and end of life care. As I refer to all of these terms in this thesis I will briefly discuss some of the issues involved in their use.

Supportive care is the broadest of the terms relating to any care a patient receives which is not directly related to diagnosis or treatment and to any stage in a potentially life threatening illness of any type, ending in cure, chronic ill health or death. Palliative care therefore is an aspect of supportive care (as are rehabilitation, psychological support, information services etc) (NICE, 2004). Since many aspects of palliative care are now held to be applicable to earlier periods in a patient's illness, its definition has become broader and potentially equivalent to supportive care.

Terminal care was commonly used for what is now understood as palliative care until the 1980s (Clark and Seymour, 1999). Terminal care now applies to the end of life once it is clear that the patient is in 'progressive terminal decline' which the National Council for Palliative Care (NCPC) suggests could be the 'last few days, or weeks, or months of life' p5 (NCPC, 1995). This rather indeterminate period presents a difficulty in interpreting what is meant by 'terminal decline'. In common usage it may be increasingly restricted to the dying phase – the last few days, e.g. a time when patients might be placed on an end of life care pathway (Ellershaw and Wilkinson, 2003).

The term 'end of life care' commonly used in the USA has become more commonly used in the UK with the introduction of the End of Life Care Programme (NHS, 2004). Recent Department of Health (DH) statements have suggested that 'end of life care' is a helpful term, since palliative care is normally associated with cancer only (DH, 2006b). National Institute for Health (NIH) in the USA indicates that it has no exact definition (Box 1-1) and the NCPC suggest that it may be better restricted to informal public 'common sense' usage (NCPC, 2006). The National Health Service (NHS) End of Life Care Programme (EoLCP) does not give a definition either; rather it states that its aim is:

'to improve the quality of care at the end of life for all patients and enable more patients to live and die in the place of their choice'(NHS, 2004).

I will discuss the emergence of end of life care as a concept in the final chapter (Section 7.3.3 page 290).

No definition of palliative care before that of Randall and Downie (2006) included an explicit statement on the temporal relationship between advanced, progressive illness and the time of death; however their term 'foreseeable future' is rather imprecise. It

is difficult to assign timescales in palliative care because of the problem in estimating prognosis for individual patients in cancer (Glare et al. 2003) and non-cancer diagnoses (Fox et al. 1999; Muntwyler et al. 2002). Lynn et al. (2000) suggest that the question ‘would you be surprised if this patient died within a year?’ is useful for identifying palliative care patients. This has been adopted by the ‘Gold Standards Framework for Palliative Care’ (GSF) to facilitate primary care teams in making this decision (EoLCP, 2006). ‘Likely to die within a year’ was the operational definition I took in 2000 when recruiting patients for the ‘emergency admissions study’ presented in Chapter-5.

It is unfortunate that there is no ideal descriptor for a patient with a chronic illness who is presumed to be in the last year of life. I use the term ‘palliative care patient’ or ‘palliative patient’; however this can be clumsy to use in narrative accounts. I use ‘end of life’, ‘dying patient’ and ‘terminally ill patient’ as general descriptions without precise definitions, relying on the common understanding of these terms.

Having defined *which* patients should receive palliative care, I will consider *what* palliative care means. Common to all definitions is the notion that palliative care should attend to the physical, psychological, social and spiritual domain, should be extended beyond the patient to the family and should aim at a global quality of life rather than some narrower clinical outcome – such as being free from pain. Quality of life is highly individual and therefore hard to define. In addition it changes over time as the patient’s disease progresses (Jocham et al. 2006) adding to the complexity of the aims of palliative care.

Such a broad definition of palliative care can lead to a lack of specificity in what specialist palliative care actually delivers and what makes it distinct from good health care delivered by conscientious generalists.

Clark has also observed that:

‘In print, in conferences, and in their daily clinical work, specialists in palliative care seem to lack clarity and confidence when defining precisely what they do and how it differs from other health care’ p906 (Clark, 2002a).

A similar point was made by Robbins:

‘If specialists actually provide something which non-specialists cannot or do not do, then the label is probably justified. However, in the case of palliative care it is not always clear what in addition specialists provide over non specialists’ p18 (Robbins, 1997).

Many palliative care skills may be possessed by generalist practitioners; however as health care interventions including those in palliative care have become increasingly complex, it is unlikely that generalists will always possess all of the skills necessary to deliver high quality palliative care. Palliative care might be considered as a generalist discipline applied to the end of life so, in the community, palliative care specialists will often act to support and supplement the work of primary care teams. Indeed palliative and primary care share many similarities, e.g. multidisciplinary working, a bio-psychosocial approach and holistic care. Both disciplines have emerged over the same time period which I will explore in Chapter-2, where I will also critique the emergence of palliative medicine as a medical subspecialty and its relationship to general practice (Section 2.4.4 page 67).

1.3 The context of the research project

The city in which the research was conducted is in the English Midlands. It has a population of 301,000 with a Black and Minority Ethnic (BME) population of 16% (English average 9.1%), the largest group being Asian or Asian British 11.3% (English average 4.6%). The city is situated on the edge of a coalfield which has only one remaining pit. Its economy is traditionally based on light engineering, which has seen a slow decline over recent years. Unemployment is near the national average and the student population is nearly twice the national average (8.7% vs 4.7%).

All of the health services central to this research are provided by the NHS.

Community health care services at the outset of the study in 2000 were organised into three primary care groups (PCGs). District nurses (DN) until 2002 were employed by a NHS community trust and worked within teams in three localities defined by PCG boundaries. In 2002 a single primary care trust (PCT) for the city was formed through an amalgamation of the health authority and PCGs. Since that time DNs and the community palliative care team have been employed by the PCT. Throughout the study period individual DNs have been attached to specific general

practices, but based in several health centres in each locality rather than in individual practice buildings.

Hospital care is provided by one acute trust, which during the period of field work was divided between two sites.¹ The smaller site was in the city centre providing orthopaedic and ophthalmic services and the city's accident and emergency (A/E) department. The main hospital on the outskirts of the city provided all other major medical and surgical specialist services including cardiothoracic and neurosurgery. The sub-regional cancer centre, which serves the surrounding area (population 900,000), was on the main hospital site. During the period of this study the hospital's designation changed from district general to university hospital following the establishment of a medical school at the local university in 2000. Patients with major medical or surgical conditions were normally taken by ambulance to the 'emergency admissions unit' (EAU) at the main hospital rather than A/E. Patients with medical conditions would frequently present to EAU directly or would be asked to attend following telephone advice either with the EAU or with a primary care professional.

Until 2002 specialist palliative care services were provided by community and hospital teams working relatively independently. Since that time the two teams have been integrated although team members are still employed by the hospital trust or PCT depending on their primary place of work. Eleven Macmillan palliative care clinical nurse specialists (CNS) work between the two teams managed by a single lead nurse. In 2005 an occupational therapist (OT) and physiotherapist joined the team in the community. Until May 2005 the Macmillan nurses worked Monday to Friday only, but since that time have provided a 7 day per week advisory and visiting service supported by an on-call palliative medicine consultant. At weekends and on bank holidays the Macmillan nurse on duty is based at the 'walk-in centre' in the city centre along with the on call GPs.

Nine inpatient palliative care beds, for which I am the consultant responsible, are available for patients from the city in a 24 bedded independent hospice in a market town 11 miles south of the city centre. Whilst the hospice does accept admissions out-of-hours, a limit on the availability of beds means that most patients in the city

¹ In July 2006 a 'Private Finance Initiative' hospital was opened in the city and all hospital services are now provided from one site.

requiring admission are admitted to the university hospital. The hospice runs a day care unit which is open to palliative care patients from the city, including those with a non-cancer diagnosis. A separate day care unit for cancer patients, who were under the care of a consultant oncologist, was located in the cancer centre although this closed in November 2005. A rota of consultants in palliative medicine provides medical cover for the hospice inpatients and also provides a 24 hour advice service for other health care professionals within the area.

During the six years in which this research has been undertaken, as well as the local developments described, much has changed within the health service in the UK which has affected the delivery of community palliative care. Two major reorganisations of the NHS have occurred with the establishment of PCTs in 2002 and their reorganisation in 2006. A new GP contract in 2004 released individual GPs from having to take responsibility for out of hours care and since April 2006 payments through the Quality and Outcomes Framework (QOF) are available for GPs having a register of palliative care patients and conducting multidisciplinary meetings 'three monthly' to review care for those patients (BMA, 2006).

Major developments in palliative care organisation have also occurred during this period. Specialist palliative care originally grew in an ad hoc manner often as a result of local charitable initiatives (Ahmed et al. 2004). Since 1987 health authorities had been expected to develop plans for local palliative care provision (Clark and Seymour, 1999), however with the publication of the NHS Cancer Plan (DH, 2000b) palliative care strategy has been more centrally driven. The Cancer Plan established sub-regional cancer networks which bring together clinicians and organisations providing cancer services, normally focused on a cancer centre (DH, 1995). Local palliative care strategy development has become increasingly undertaken by cancer network palliative care strategy groups which include representatives from independent hospices. In 2003 - 2007 cancer networks were responsible for administering a £50 million budget for the development of palliative care.

In 2001 a new initiative, the Gold Standards Framework for Palliative Care (GSF) (Thomas, 2003), arising out of the Macmillan GP facilitator programme (RCGP, 1995) was developed. This is an integrated framework which enables primary care practices to focus on important aspects of palliative care such as: identification of

palliative patients, communication, advance care planning, support for carers and care of the dying. GSF has been remarkably successful. Since national dissemination commenced in 2003, between 20% and 30% of practices in England have enrolled with GSF (Munday and Dale, 2007), although in the city only two practices are taking part. GSF now forms part of the 'End of Life Care Programme' (EoLCP) within the NHS (England) established in 2004 (NHS, 2004), along with two other tools which aim to improve community palliative care; the 'Liverpool Care of the Dying Pathway' (LCP) (Ellershaw and Wilkinson, 2003) and the 'Preferred Place of Care Tool' (PPOC) (Storey et al. 2003).

Whilst palliative care for non cancer illnesses has been discussed in official documents (DH, 1992) and by professionals (George and Sykes, 1997; Addington-Hall and Higginson, 2001) over a number of years, in the last six years it has been given greater prominence through the publication of 'National Service Frameworks' (NSF) for various chronic conditions starting in 2000 with the NSF for coronary heart disease (DH, 2000a). With the publication of the White Paper on community care in 2006 the UK government announced their intention of making high quality palliative care available to all patients, irrespective of diagnosis, and confirmed their commitment to enabling all patients to die in their place of choice (DH, 2006a).

Community palliative care is fundamentally provided by the GP, DN and the community palliative care CNS. This seems to be the dominant model throughout the NHS, described as the 'supportive triangle' by Burt et al. (2005). The 'supportive triangle' is central to this thesis, highlighted in both patient and professionals narratives. However, I will also highlight the importance of a fourth member of the team who provides community palliative care. This is the health care assistant (HCA) who within the city provides 'sitting services' to allow patients to remain in their homes (Chapter-6). HCAs have been described as invisible workers within the NHS (Thornley, 1997) and it seems that this is no less true for HCAs working within the palliative care setting, judged by the paucity of research into their roles within the discipline.

1.4 Continuity of care

High quality community palliative care should be experienced by patients as being coherent and well coordinated - the essence of continuity of care (Haggerty et al. 2003). Continuity of care for palliative care patients is challenging to achieve because of their complex needs and the wide range of professionals involved in their management. This is illustrated by one study of 50 patients admitted to a hospice who had seen an average of 32 doctors (range 13 – 97) in the time since their cancer diagnosis. Patients with a history of less than a year, i.e. those diagnosed at a late stage had seen an average of 28 doctors. This study did not report on the number of nurses and other clinical staff seen (Smith et al. 1999).

In the introductory chapter to our book ‘Continuity in palliative care: key issues and perspectives’ (Munday and Shipman, 2007a), drawing on the recent work of Freeman’s team (Freeman et al. 2000; Haggerty et al. 2003), Cathy Shipman and I have suggested that for palliative care there are two key elements of continuity: *longitudinal continuity* – continuity over time and *cross sectional* continuity: continuity between practitioners and between teams (Box 1-2).

Continuity is predicated on practitioner relationships and clinical systems. The overall patient experience of ‘connected and coherent care’ (or otherwise) will emerge from the quality of those relationships, the effectiveness of the information systems involved, the effectiveness of management strategies and the maintenance of (or interruptions in) continuity of place. The needs of individual patients and the work of professionals to meet them will vary and will change through time.

Outcomes will therefore be highly contingent on the context and individual features within it. In addition, since good communication and multidisciplinary teamwork are central to achieving continuity, continuous monitoring of services to enable problems to be identified and learning to take place is essential (Munday, 2002a).

Longitudinal continuity is continuity over time and includes:

Relational:* - personal continuity maintained by an individual e.g. GP or community nurse, or continuity maintained by a small team of professionals personally known to the patient.

Information:* - records, letters etc. but also informal information - facts retained by professionals but not written down.

Management:* - coherent, consistent and logical clinical interventions maintained and adjusted over time, rather than haphazard and uncoordinated.

Place: enabling a patient to remain at home or to be admitted to the same ward or hospice so that relational continuity may be maintained, respecting patient choice as far as possible (Rogers et al. 2007).

Cross sectional continuity occurs 'in the moment'. Patients may be receiving care *simultaneously* from many professionals, e.g. GP, DN, Macmillan nurse, oncologist and hospice day care unit. Cross sectional continuity includes:

Continuity within a team: a single multidisciplinary team ensures that the care they offer is coordinated.

Continuity between teams: care is coordinated between primary, secondary and tertiary care teams and with teams providing out of hours care, by maintaining communication, cooperation and respecting the function of other teams.

* - identified as fundamental aspects by (Haggerty et al. 2003).

Box 1-2 - Aspects of continuity of care

Continuity is an important issue in the empirical studies in this thesis. In Chapter-5 all patients had recently experienced 'discontinuity of place' having been admitted to hospital. Patient narratives illustrate the importance of relational continuity with DNs, Macmillan nurses and GPs and oncology ward staff. Providing continuity to patients and their families was important for many HCAs in the study reported in Chapter-6, as it enabled them to build supportive relationships with them.

Continuity in palliative care is an important and complex concept. In order for continuity to be maintained, practitioners need to be aware of its multifaceted nature and to understand the underlying dynamics involved in its maintenance.

1.5 Complexity theory: a brief introduction

Complexity theory provides a useful conceptual tool for exploring the dynamics involved in delivering holistic continuity of care to palliative care patients in the community. It is also applicable to many other aspects of palliative care, some of which we have discussed in a previous publication (Munday et al. 2003).

Complex systems are composed of many elements which interact in an *unpredictable* and non-linear fashion.² The structure of the system is continually emerging from those interactions. This distinguishes complex from complicated systems such as a television set, which has many elements interacting in a *predictable* fashion. The elements in a television are hard wired so that when the set is turned on, a predictable outcome occurs. Whilst the elements in a complex system do not interact in an ordered and predictable way, neither do they interact in a completely random fashion (such as with gas molecules in a cylinder). Complex systems are neither ordered nor random but exist partway between the two (Holt, 2004).

The non-linearity arises in a complex system because interactions between two elements are affected by interactions with many other elements. Understanding complex systems has been facilitated by computer simulation, which enables the emergence of 'basic' complex systems to be modelled. Before the advent of this technology, little was known about complex system behaviour (Cohen and Stewart, 1994).

² Linear systems can be denoted by simple equations eg. $y=3x$. In this the output is proportional to the input. In non-linear systems there is no such proportionality.

- Complex systems consist of a large number of elements.
- Elements interact with each other dynamically such that the system changes over time, i.e. the features of the system “emerge” over time from these interactions.
- Interactions are normally “short range”, elements interacting with others close by.
- The interaction is fairly rich, i.e. any element within the system influences and is influenced by quite a few others.
- Interactions are non-linear. Small incremental changes may have large effects and conversely large incremental changes may be absorbed leading to little effect.
- Negative (inhibiting) and positive (enhancing) feedback loops develop in the interactions magnifying the effects of some interactions and dampening down others.
- Complex systems interact with their environment forming unclear boundaries with small systems nested within larger systems, e.g. a palliative care team within a PCT.
- Complex systems operate under conditions far from equilibrium (or stasis), so that they constantly change and evolve.
- The history of a complex system has a major impact on its ongoing development.
- Each element in the system is ignorant of the behaviour of the system as a whole. It responds only to information local to it, but control of the overall system tends to be distributed throughout the system.

Box 1-3 - Features of complex systems - adapted from Cilliers (1998)

Whilst examples of complex systems may be found in many diverse domains – weather (Palmer, 1992), biology and ecology (Kauffman, 1995), organisations (Morel and Ramanujam, 1999) and the economy (Buchanan, 2000) – and each will behave in ways specific to its own domain, complex systems also have common features. These are summarised in Box 1-3 (Cilliers, 1998).

Thus, complex systems evolve over time in an unpredictable, though not random fashion as a result of the interaction of the many elements which make up the system. The behaviour of the system is therefore ‘emergent’ and is irreducible to its individual elements. Thus a reductionist approach is liable to fail in both being able

to explain how a system has emerged into its present form and in predicting how it will evolve. This lack of predictability explains why the weather is so difficult to forecast despite sophisticated equipment; the accuracy decreasing the further into the future the forecaster tries to predict.

The history of a complex system is important for determining its future behaviour because the system exists as a totality of all the past interactions within it, thus:

‘Two similar systems placed in identical conditions may respond in vastly different ways if they have different histories. To be more precise, the history of the system is not merely important for understanding the system, it codetermines the structure of the system’ p108 -109 (Cilliers, 1998).

Small perturbations in the system may have a seemingly disproportionate effect on its emergence,³ conversely large inputs may be ‘absorbed’ into the system with little effect on its future state.

Complex systems have indistinct or fuzzy boundaries and overlap and interlock. For instance a person may be a member of different social groupings, family, work, leisure organisations etc. The influence of one system may have a direct impact on the functioning of another, for example the effects of events in family life may be felt in the work place. In addition complex systems are ‘nested’ within each other: a person is nested in a family, is nested in a neighbourhood, is nested in a city etc. Each of these is a complex system in its own right with emergent properties and fuzzy boundaries. The evolution of one system will affect the evolution of another, i.e. systems will co-evolve. Thus the development of a hospice over time will be affected by the evolution of the local and national health system, which might also be affected by the evolution of hospices.

³ This has been popularly called the butterfly effect. Based on computer modelling a butterfly which flaps its wings in Brazil, over time will potentially lead to the weather system in Texas producing a storm or a calm (Lorenz, 1995).

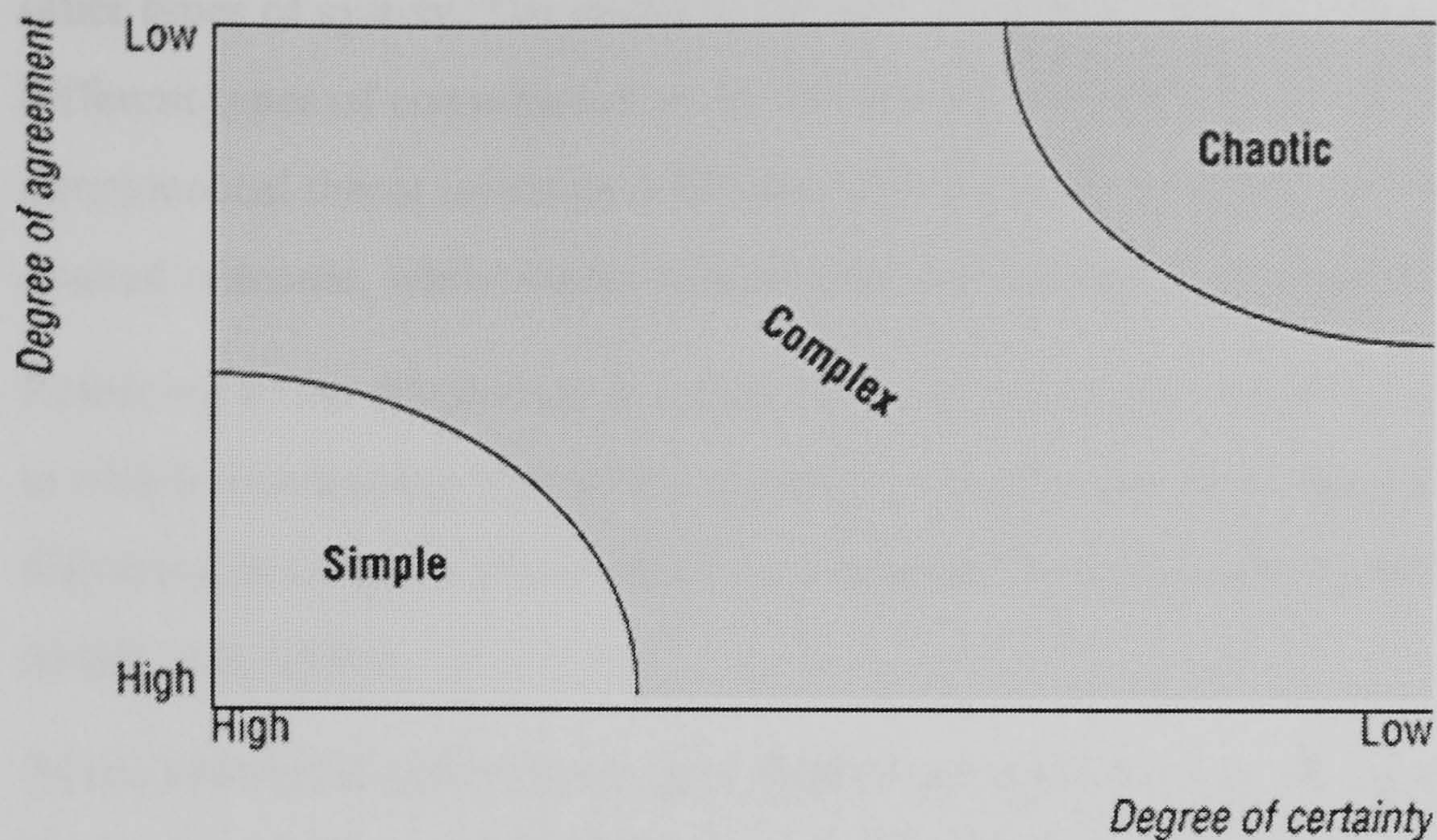


Diagram adapted from Stacey 1996 p46 and Plsek and Greenhalgh 2001

Note:

This diagram was originally designed to explore organisational decision making. Decisions which are simple can be made when there is a high degree of certainty in the outcome and a high degree of agreement. As issues become more complex certainty of outcome reduces and decisions are no longer simple. Agreement may still be achieved on ideological grounds.

The diagram by illustrating the space between order (simple linear systems) and chaos, presents a useful conceptual tool for considering complex phenomena.

Figure 1-1 Diagrammatic representation of simple, chaotic and complex spaces

A useful tool for representing complex systems is the diagram originally constructed by Stacey to illustrate decision making in organisations which has been applied to health care decision making by Plsek and Greenhalgh (Figure 1-1) (Stacey, 1996; Plsek and Greenhalgh, 2001).

Simple systems in which there is a high degree of certainty, predictability and agreement are located in the bottom left hand corner of the diagram. An extreme example might be a military unit on the march. The exact position of the unit and each element (soldier) within it is predictable into the future as long as the speed and direction of each element is known. Conversely, the top right hand corner represents systems which are totally random and in which no prediction is possible with the system likely to breakdown into chaos, such as when a group of teenagers is no longer held together by organisational ties, e.g. a school class or by a common interest and their identity as a group breaks down. In the middle is the zone of complexity, also sometimes termed the 'edge of chaos' p27 (Kauffman, 1995) where complex (i.e. most) organisations exist. The Stacey diagram is useful for modelling

other types of system. For instance Innes et al. (2005) used the diagram to explore different types of consultation in the GP setting. Simple consultations such as for a streptococcal throat infection will have high levels of certainty and agreement as to desired outcome, whilst stress related disorder is likely to be more complex.

Returning to the discussion of complexity and continuity in palliative care, the way in which overlapping and nested systems co-evolve can be illustrated as in the following description which involves a gradual ‘focusing out’ from the patient to the health care system.

At the individual patient level care needs to be well planned with attention to detail for continuity in terms of relationship, information and management. The patient, however, is embedded within the context of their family and other immediate social relationships. Continuity similarly needs to be maintained for individuals and groups close to the patient. Care for the patient and family ‘meshes in’ with the activity of the professionals and teams caring for the patient. There might be several of these, for example from primary care, from the disease site specialty area and from specialist palliative care. These teams overlap as they care for the individual patient, but they are also part of wider health care organisations, which may be institutionally related or diverse (e.g. PCT, acute trust, voluntary hospice etc). The individual teams in their organisations will operate within the wider health care system at a local, regional or sub-regional network and national level. All of these systems from the patient up to the national level have indistinct boundaries and are continuously changing and evolving. Changes at one level will have an effect at another so that no part of the whole can be isolated and ‘engineered’ without ultimately affecting the whole system (Salisbury, 2007).

I will draw on complexity theory explicitly in the final chapter as I consider a theoretical framework for the emergence of the community palliative care team as a community of research practice (Section 7.6.1 page 303). However, insights from complexity have influenced my understanding of the complex nature of community palliative care practice, which runs throughout this thesis, although this is not always explicit. My discovery of complexity theory in 1999 has thus influenced my approach to scientific inquiry and I will describe aspects of this intellectual journey.

1.6 Personal professional history: clinician - researcher

My principle professional role is within clinical medicine. For a number of years I was an anaesthetist, a specialty which is grounded in a clear understanding of linear cause and effect. Anaesthetists have an intimate and detailed knowledge of what will happen when drug A is given in dose B by route C to a patient with characteristics D. In 1992 I entered general practice which was beginning to be strongly influenced by the novel discipline of 'evidence based medicine' (EBM). As a GP trainee I continued to have a belief that uncertainty could be substantially reduced through research and concluded that EBM was the key. Through experience I began to realise increasingly how complex general practice is and how complex problems cannot be reduced to simple solutions. This led through a series of steps to an interest in complexity theory as an explanatory framework and an interest in qualitative research as a means of exploring and achieving greater understanding of complex contexts (Munday, 2000). Whilst undertaking this thesis and arising out of my interest in complexity theory I developed an interest in critical realism as an approach to understanding complex causation (explored in Chapter-4).

As a GP I developed a special interest in palliative care and issues related to the out of hours delivery of primary care to palliative care patients (Munday et al. 1999). This was the start of my emergent research interests ultimately leading to the studies presented in this thesis. This interest developed further when I moved from general practice into specialist palliative medicine in 1998, first through a national survey of GP co-operatives and a parallel study of palliative care units, exploring both the activity of GPs and the interface with specialist palliative care (Munday et al. 2002; Munday and Shipman, 2007b). Working with the National Association for GP Co-operatives (NAGPC) presenting some of the findings from these surveys at their annual conference, I was invited by them to facilitate a series of workshops to develop guidelines for palliative care delivery (Munday, 2002b). Through this work an interest in the complexity involved in delivering continuity of care for palliative care patients began to emerge.

The first research project presented in this thesis (Chapter-5) was conceived following an audit which I undertook in March 1999 within the university hospital

(described in Section 1.3) in which I was working as a specialist registrar in palliative care. This is also where the research was subsequently conducted.

The audit conducted over a two week period was designed to look at the effectiveness of symptom control for patients within the first 24 hours following admission. Nineteen patients with cancer and 20 with a non-cancer diagnosis were identified. Whilst the results demonstrated a variable quality of symptom control (Munday et al. 2000), what was unexpected was the proportion of patients admitted through self referral to the ambulance services 18/39 (46%) rather than admission through the GP 19/39 (48%). For the remaining two patients, route of admission was unclear.

As I had been a GP until the previous year, albeit in a different part of the country, it seemed to me that a high proportion of patients admitted had bypassed the GP. These patients all had chronic illnesses and would presumably have been high users of community services including their GP. Whilst in my experience it was not unusual for patients in this group to be admitted as emergencies, it was unusual for the GP or the out of hours GP service not to be involved unless the patient suffered a collapse or sudden deterioration. We therefore compared the triage status made by EAU staff for the two groups but found no obvious difference between them (Figure 1-2).

Little was known about the processes in the community which led to patients being admitted as emergencies (as I describe in Chapter-3). The fact that many patients were keen to recount their story to us whilst conducting the audit and since it was possible to interview them on the ward, a qualitative study to explore patients' narratives regarding admission seemed feasible. The audit therefore acted in part as a feasibility study for the study into the reasons for emergency admission of palliative care patients to hospital (Chapter-5).

Emergency Admission Unit Triage According to Route of admission

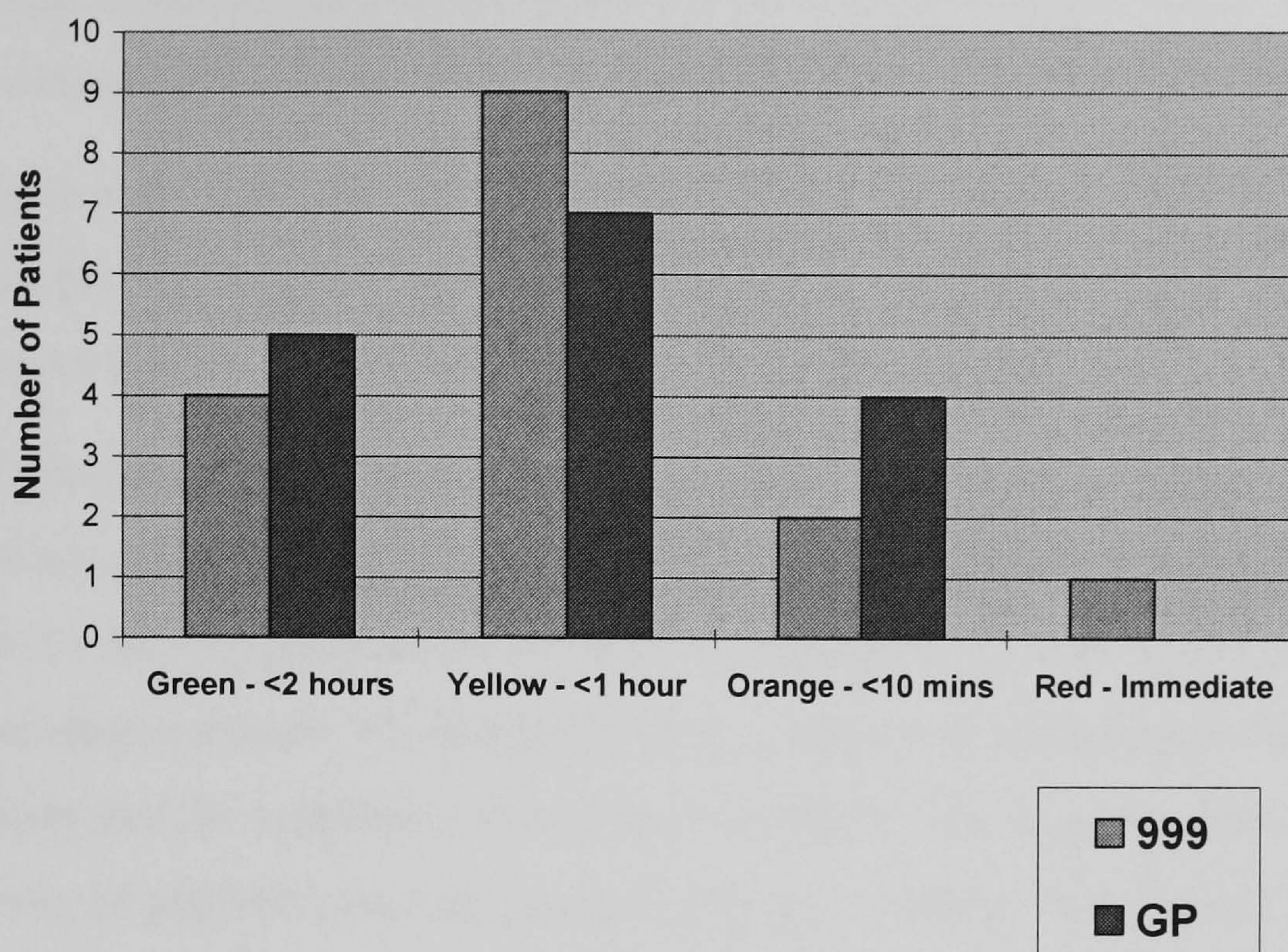


Figure 1-2 - Audit of Palliative Care Admissions - Triage Results

1.7 Overview of Thesis

The rest of the thesis has three parts: Chapters 2-4, 5-6 and 7. Chapters 2 to 4 give an overview of the empirical and methodological literature pertinent to the thesis, Chapters 5 and 6 present the empirical studies and Chapter-7 is the final discussion.

Ann Borsay said ‘neither medical knowledge nor medical practice operates in a vacuum, both are socially contingent’ p69 (Borsay, 2001), an observation resonant with the concept of emergence in a complex system; thus an exploration of the historical development of a service might facilitate the understanding of its present functioning. I have adopted this approach in Chapters 2 and 4 which start with a historical exploration – from 1948 onwards – of the parallel development of primary and palliative care in the community (Chapter-2) and the history of randomised controlled trials (RCTs) in health services research and palliative care (Chapter-4).

Chapter-2 continues by exploring the general literature of community palliative care whilst Chapter-3 is a systematic review of the literature regarding the reasons for admission of palliative care patients into hospital, which links with the research presented in Chapter-5.

After exploring RCT research in Chapter-4, I discuss complex causation as understood in critical realism. Critical realism presents a useful framework for exploring the ontological depth of the social processes inherent in the delivery of palliative care which along with its explicit view of epistemology makes it, in my view, a promising philosophical basis for multi-method palliative care research.

In Chapters-5 and 6 I present the results of the two studies which form the empirical heart of this project, both of which adopt a narrative approach to explore the experiences of patients, carers and health care professionals (HCP).

Chapter-5 presents a multi-method study exploring the reasons for admission of cancer and non-cancer palliative care patients into hospital beds. In the introduction to Chapter-5 I explore the concept of the illness narrative, plus the utility of using a 'critical incident approach' to studying patients' narratives concerning events leading to admissions and the complex contexts surrounding it. The study has three parts: first, a survey of palliative care admissions over five sample weeks spread over six months; next, a narrative study with a selection of patients and carers identified in the survey; finally key informant interviews with HCPs involved in the care of these patients which enabled some of the issues arising from patient and carer narratives to be explored in the professional context. Chapter-5 concludes with an exploration of the power relationships between HCPs and patients and amongst HCPs apparent in the narratives recorded.

Chapter-6 explores the narratives of health care assistants (HCAs) caring for palliative care patients in their own homes. This study was part of an action research project undertaken by members of the palliative care team and HCAs, designed to develop support and education for them. Fifteen HCAs were interviewed in order to explore in detail the issues which had been emerging from the action research group, which had been restricted to two HCAs only. The interviews enabled the complexities of the HCA role to be explored at a practical and theoretical level and illustrated the importance of understanding issues of power and emotion inherent in their work when developing support structures for them.

Whilst I had overall leadership of the project the HCA interviews were undertaken jointly by the home care facilitator, who has responsibility for developing support

systems and training for HCAs and a research fellow who was working with us on this project. I present my own analysis of the interviews in Chapter-6.

Chapters 5 and 6 contain a discussion pertinent to each study. In the final chapter I therefore discuss some of the broader methodological issues and empirical findings emerging in this thesis. I discuss the importance of narrative in the construction of social histories which enables an exploration of the emergence of social structures and discourses over time. I also explore the importance of narrative in cognitive maps used in understanding complex reality. Finally, I explore the development of the community of research practice within our community palliative care team through which service development and research have be linked.

Chapter 2 - Literature review: the historical emergence of community palliative care

2.1 Introduction

This thesis explores the development of community palliative care and the place of practitioner based research in this process. In Section 1.5 (page 29) I argued that community palliative care is best considered in terms of complex interacting systems, since this provides conceptual tools for understanding such complex issues and has implications for research and development in community palliative care. One important feature of complex systems is that future developments are predicated on the system's history. For this reason I will examine the history of community palliative care, taking as my starting point the inception of the NHS in 1948, since it was at this point that the modern health service began providing care, 'free at the point of use', 'from cradle to grave'.

Using this time frame enables an examination of the emergence of both the concept of holism in health care and the multidisciplinary team central to its delivery. These developments reveal remarkably parallel features between primary care (particularly general practice) and specialist palliative care. In addition this historical approach enables a critique of the development of primary and specialist palliative care to be made, facilitating the interpretation of current studies of palliative care provision and patient and carer experience in end of life care.

David Clark and those involved with the Hospice History Programme¹ have published detailed accounts of the history and development of hospices and palliative care, particularly charting the work of Dame Cicely Saunders and other significant figures of the early hospice movement. However, no specific accounts of the parallel development of primary and palliative care have been published, therefore this review also aims to provide an addition to this historical evidence base. Similarly, no account has been published which charts the development of palliative care research. This is discussed in Chapter-4 starting also from 1948, since this was a landmark year for modern health services research with the publication of the results of two ground breaking Randomised Controlled Trials (RCTs) (Doll, 1998).

¹ <http://www.hospice-history.org.uk/main.htm> (Accessed 05/03/07)

Following the historical review I will review current community palliative care as provided by GPs, district nurses (DNs) and palliative care community clinical nurse specialists (CNSs) ending with a brief review of multidisciplinary working in community palliative care.

2.1.1 Literature sources

Several literature sources have been accessed for this chapter using different search strategies. For the historical review, in palliative care I have used Clark's work extensively as a secondary source and have accessed primary sources from the bibliographies of these publications. In addition the bibliographies of the primary sources have provided additional references. As a source for primary care, I have used Loudon et al. (1998) 'General practice under the National Health Service 1948 – 1997,' the historical work of Armstrong (1983) 'Political anatomy of the body' and archival records on the RCGP website, following references from all of these to locate primary sources. In addition I have used Rivett (1997) 'From cradle to grave: fifty years of the NHS' for a general history of the NHS. Particular account was taken of any references in the primary care literature which referred to palliative care and vice versa.

Whilst my lack of training in the historical method is a drawback and space does not allow a very detailed discussion of the issues, using multiple sources has enabled triangulation of the available accounts and ratification of the coherence and consistency of the overview.

For the review of current community palliative care I have used the wide range of sources which I have collected over 10 years of work and study in palliative medicine. During this time I have built up a wide database (>1200 references) of relevant material which is fully searchable. I have also used electronic searching frequently during this project as well as in preparation of the book 'Continuity in palliative care: key issues and perspectives' (Munday and Shipman, 2007a).

2.2 Historical periods in the development of Palliative Care

Reviewing the historical literature of primary and palliative care suggests that the 60 years since 1948 broadly fall into three periods of 20 years. The years 1948 – 1967 form the period before both primary care and palliative care were established as

entities. During this time both disciplines were being developed as philosophical concepts by their early pioneers who were also working towards their realisation. This period is bounded by the inception of the NHS and the 1966 GP charter, from which 'primary care' emerged, and the founding of St Christopher's hospice in 1967 - the defining moment of palliative care as a clinical discipline.² Following this period, 1968 – 1987 were the years of rapid development for palliative care, first in the hospice movement and later in community services. Similarly these were years of development and consolidation for primary care as a professional and academic discipline. This period ended with the formation of palliative medicine as a specialty in 1987; the 1990 NHS reorganisation which included the 1990 GP contract; and Project 2000 adopted in 1988. All of these developments held major implications for both primary and palliative care, with the new emphasis on evidence and efficiency in the NHS and redefinition of professional roles. The years since 1988 I will consider as the current period for palliative and primary care.³ For this last period I will consider in detail the literature surrounding GPs, DNs and palliative care CNSs and the concept of the multidisciplinary team working.

2.3 1948 – 1967: Conceptual development of primary and palliative care

I start with a brief overview of general practice and district nursing in general during this period, their relationship to one another and to the care of the dying provided by GPs and DNs, before turning to issues of care for the dying in the community.

2.3.1 General practice 1948 - 1967

The roots of general practice providing care free to all in the UK was heralded in 1912, with Lloyd George's National Insurance Act (Hart, 2000). Through this act, employed workers were provided with prepaid medical care by a GP. However, this did not extend to their families who still had to pay. With the advent of the NHS on 5th July 1948 free health care became accessible for all. This had immediate effects for the population, especially the poorly off.

² Although the term "palliative care" was first used in the 1970s by Canadian surgeon Balfour Mount (Ferris et al. 2002), the term palliation was already in current usage e.g. (Gavey et al 1955).

³ Although we appear to be entering the new period of 'End of Life Care' as discussed in Section 7.3.3 (page 290).

‘For patients, particularly the lower middle class, the NHS was deliverance from their biggest single cause of personal bankruptcy’ p545 (Hart, 2000).

Whilst it is reported that doctors were antagonistic to the establishment of the NHS with Aneurin Bevan, the Minister of Health, allegedly claiming that he had to ‘stuff their mouths with gold to get them into the NHS’ (Toynbee, 2003), it seems that the truth is more complex (Rivett, 1997). Fulton reports that the BMA rather than being fundamentally opposed, had given ‘precision and direction towards a national, comprehensive scheme’ p1285 (Fulton, 1998), publishing in 1933 its ‘Essentials of a national health service.’ The antagonism seemed to be related particularly to proposed contractual conditions. The Dawson report of 1920 had proposed a central role for GPs within community health centres, which GPs had supported, but the fact that the plan in 1946 involved them being managed by medical officers of health (MOH) of the local authorities⁴ and the loss of independent practitioner status led to opposition towards the scheme (Webster, 1998).

Prolonged negotiation with Bevan led to a compromise; whilst hospitals were nationalised and managed under a regional system, GPs – along with dentists, opticians and pharmacists - maintained their independent contractor status (Rivett, 1997). GPs’ activities were regulated by executive councils, which largely retained the same membership as the pre-NHS National Insurance committees (Collings, 1950). Morrell suggests that whatever the official response to the NHS and in spite of the continuing resentment, ‘most [GPs] considered it their duty to make it work for the sake of their patients’ p1 (Morrell, 1998). The third section of the NHS was under the control and management of local authorities and included community nursing services – district nursing, midwifery and health visiting, and other community services such as the school medical and dental service.

The most detailed account of general practice at this time is provided by Collings (1950) who reported a large case study⁵ survey of general practice in three areas of provincial England, one area in the north, one in the north west and one in the south:

⁴ The antagonism and mutual suspicion between GPs and the Local Authority MOH is described by many historians of the period, and immortalised in the open warfare apparent between Dr Cameron and Dr Snoddy in AJ Cronin’s “Dr Findlay’s casebook”.

⁵ The report extends to 30 pages in an edition of the Lancet.

‘selected so that a mosaic might be constructed which would present the general picture’ p555 (Collings, 1950).

This study was undertaken one year after the establishment of the NHS. Of the practices studied: 16 were ‘industrial’, 17 ‘urban residential’ and 22 ‘rural’, varying in size from single handed to several partners, and GPs’ personal lists from 800 to 4000 patients - the maximum allowed at the time. The majority of practices he considered to be deficient in some way or other. Julian Tudor Hart, a veteran and highly respected GP, writing 50 years later paints a similar picture to Collings’ based on his experience as a GP through the late 1950s onwards (Hart, 2000; Hart, 1998).

The worst performing practices were industrial, commonly practicing from within a converted shop with a waiting room and one consulting room. The conditions were cramped, often dirty and poorly equipped. Patients would queue up in the waiting room and often outside in the street at busy times. Often the GP worked on his own, or with a house keeper whose function was to keep order and to lock the door at the end of the appointed surgery time – leaving those outside to return at a later date (Hart, 2000).

Clinical practice was often perfunctory, with GPs seeing patients for one or two minutes, handing out sickness certificates with little questioning and ending the consultation with a ‘bottle of medicine’. Clinical records were not kept and often patients in whom the GP suspected a serious clinical condition were not examined but referred to the hospital with a hand written note (Collings, 1950). Large numbers of home visits were also undertaken with similarly rapid consultations. Even in the best practices GPs might see between 30 and 50 patients in the morning and evening with more than 30 visits between surgeries, still leaving time for lunch (Hart, 2000; Collings, 1950).

The elderly and chronically sick were particularly wont to be labelled as ‘hopeless cases’ and little thought given to their medical conditions. Although domiciliary visits from consultant staff were possible to arrange, often these were not thought worthwhile as GPs considered there was nothing else the consultant could add (Collings, 1950).

Rural and urban residential areas had more pleasant surgeries although these were also often poorly equipped and the clinical standards were at times equally as poor.

Better doctor patient relationships seemed to exist in these areas with GPs being more familiar with their patients and their families and continuity of care more in evidence. In addition, GPs in rural areas often had access to cottage hospital beds where they were able to admit patients and perform surgery.

Whilst poor practice seemed to be the norm, marked variation in standards existed. Some practices were described as very good, with longer and less rushed consultations; the GP displaying good clinical skills, examining patients appropriately and exploring issues in depth with them. These practices typically performed minor surgery within the practice and simple laboratory tests, e.g. microscopic examination for infection. However, where the GP opted to have a smaller list and give more time to patients, practices seemed hardly financially viable.

Collings (1950) suggested that poor practice was a symptom of a poor system in which the nature of general practice and its minimum standards had not been clearly defined. These problems had predated the NHS, but the increase in demands on GPs because of higher list sizes had pushed some practices towards breaking point. In his opinion without tackling these, general practice would continue to decline. He surmised that:

‘The greatest single threat to the future of general practice is the gap between the general practitioner and the specialist. This gap has been widened by the impetus given by the Act to hospital development, and the simultaneous neglect of general practice as an issue of policy’ p571 (ibid).

The NHS Act 1946 led to a division between specialist medicine and general practice. GPs lost their admitting rights to hospitals and retained these only in rural cottage hospitals (Hart, 2000). GPs frequently did not have access to diagnostic laboratory tests, needing to refer patients to a specialist for investigation.

Paradoxically, the closer the practice area was to teaching hospitals the poorer the quality of service offered (Collings, 1950). Since young doctors could not easily enter general practice except as assistants, Collings feared their ability to challenge and change practice would be so curtailed, the greater danger was that the system would change them into poor clinicians.

Little changed in policy towards GPs within the NHS until the 1960s, since most of the energy and funding was devoted to developing the hospital service (Webster, 1998). The proposed health centres did not materialise, causing Collings to comment:

‘Many practitioners now regard the promise of health centres as a political trick, designed to gain their support at the time of the negotiations, or at least as an unfulfilled promise whose fulfilment is now unlikely’ p575 (Collings, 1950).

By the 1960s 15 years of confrontations over pay between profession and government ‘induced an atmosphere of mutual suspicion’ p23 (Webster, 1998). The lack of commitment to developing general practice is starkly illustrated by the fact that ‘even in 1961 out of the 2320 headquarters staff of the Ministry of Health, only fourteen were dedicated to general medical practice’ p23 (ibid). Capitation fee payments little changed from 1911, rewarded practices with larger list sizes which also incurred the minimum practice expenses; this did not encourage good care or innovation.

Change finally came in 1966 with the family doctor charter, negotiated and largely accepted on the basis of a proposal made the year before by the BMA (BMA, 1965). Whilst several reports on improving general practice had been produced in the early 1960s and the Ministry of Health were indicating more inclination to support the development of general practice, it was a crisis of recruitment and GPs threatening to resign from the NHS which forced the government’s hand (Hart, 1998). The GP Charter provided a fairer system of remuneration and reimbursed practice expenses for ‘ancillary staff’ which allowed GPs to employ nurses within the practice. It paved the way for the development of the primary care team and remained largely in place until the 1990 reforms (Webster, 1998).

In the early 1950s a number of GPs saw that ‘salvation would not come until general practice had its own college and set its own standards, based on reliable facts’ p214 (Drury, 1998). GPs received scant support for this venture from the other medical royal colleges; however Drury reports that there was sufficient support both within and outside general practice for the College of General Practitioners to be established on 1st January 1953.

Its first president was William Pickles, renowned for his epidemiological study into an outbreak of hepatitis in his general practice in Wensleydale in 1933 (RCGP,

2006). Other early members included John Fry, who conducted and published a survey of one year's morbidity within his south London general practice (Fry, 1952). The college existed to encourage academic work and research, leaving the General Medical Services Committee of the BMA to represent GPs' contractual interests (Morrell, 1998). The membership in early years only amounted to 10% of GPs, not reaching 50% until 1990 (Drury, 1998). However, Hart reports that for the 'few believers' in general practice, the college 'seemed like a candle in otherwise total darkness' p1285 (Hart, 1998).

Fundamental to the development of general practice in the 1950s and 1960s was the work of Michael Balint, a psychoanalyst from the Tavistock Clinic (Marinker, 1998). Publishing 'The doctor, his patient and the illness' in the *Lancet* in 1955 (Balint, 1955) and in a book in 1957 (Balint, 1957), he highlighted the psychological and social aspects of the work of general practitioners. Patients consulting the GP would present with a constellation of symptoms not yet formed into a diagnosis. The underlying reason for the distress leading to consultation could be physical, but also psychological or social. The skill of the GP was in knowing what to explore in the patients' story, where to probe and at what speed. Treatment offered by GPs not only came in bottles, but the doctor himself was like a 'drug' in the patient's treatment. Balint's thesis was that the specific pharmacology of the 'doctor as drug' p866 (Balint, 1955) needed to be understood in detail. His work 'provided the basic text for the pioneering generation which founded the College of General Practitioners' p553 (Hart, 2000), gave substance to the definition of general practice as a discipline in its own right and engendered its particular 'psychosocial gaze' (Armstrong, 1979), emphasising the central position of the consultation and consulting skills in the GPs craft (Bosanquet and Salisbury, 1998).⁶

Soon came calls for academic departments of general practice, principally to enable the development of postgraduate training programmes for GPs (McWhinney, 1966). The training was not to be based on isolated exposure to a spectrum of hospital specialities as if 'the general practitioner is a pale image of a number of different specialists' p421 (ibid), but was to be integrated and under the guidance of a general practitioner of 'good academic standing' p422 (ibid). The Royal Commission for

⁶ I explore this in more detail in Section 7.3.3 (page 290).

Medical Education in 1968 recognised general practice as a specialty in its own right and recommended vocational training for GPs and the establishment of post-graduate medical centres nationwide. Subsequently, formal three year GP training along the lines suggested by McWhinney developed through the 1970s, becoming compulsory in 1982 (Gray, 1998).

2.3.2 District nursing 1948 - 1967

The roots of district nursing lay 90 years before the NHS, when a service to the poor in Liverpool was established in 1859. The concept rapidly spread through other areas, and a gift in 1877 of £70,000 as part of Queen Victoria's golden jubilee led to the founding of the Queen Victoria Jubilee Institute for Nurses (Queen's Institute of District Nursing from 1929). The role of this body was to provide education for nurses to attend 'the poor sick' and to promote district nursing branches throughout the UK. In addition to 'sick nursing', DNs had a public health role - monitoring the health of children and in the prevention of epidemics; many also worked as midwives. The Queen's Institute established a DN certificate in 1955 (Lamb, 1977).

District nursing services were provided by local associations and funded by charitable donations. In time, families were encouraged to pay what they were able. Growing out of this, a 'provident system' developed through which households paid one or two pence per week and thereafter received free care, with maternity care costing extra. However, a condition for affiliation to the Queen's institute was that the poor without means to pay must be given free care (Wilmshurst, 1943). GP financial interests were protected by an Act of Parliament, which made it the duty of the nurse to refer to a GP if medical help were needed (Jeffreys, 1998). By 1936 district nursing was available throughout the UK and the three sections: midwifery, health visiting and sick nursing had evolved. At the inception of the NHS, district nursing became the responsibility of local authorities under the control of the MOH with the role of the DN changing from caring for the 'sick poor' to any of the population needing nursing at home (Lamb, 1977). In addition, the inherent conflict between GPs and DNs was replaced by co-operation (albeit rudimentary – see below), with district nursing seen to possess a dual function: to support the GP, economising his time and to help avoid hospital admission, such that 'ordinarily a

nurse is summoned by the family doctor and works under his direction' p70 (Grundy, 1964).

Any sense of team working and shared responsibility in the early NHS was therefore subsumed under the hierarchical relationship, between doctor and nurse. In the 1943 edition of the Handbook for Queen's Nurses, any idea of negotiation between nurse and doctor is absent; the nurse would act on the doctor's orders and not question a doctor's decision:

'If there are any signs of haemorrhage [in a cancer patient] the doctor should be asked if he will provide a styptic, and, if he will, the friends [of the patient] should be shown how to apply it' p36 (Wilmshurst, 1943).

Grundy summarised the situation (with seemingly no irony intended) 'the home nursing service, in other words should be regarded as a handmaid of the family doctor' p70 (Grundy, 1964).

Whilst DNs worked under the direction of the GP, there was little contact between them. As DNs were directly employed and managed by the local authority and GPs were independent practitioners contracted to provide medical service to their patients, the geographical boundaries of their practice were often very different, with DNs not uncommonly seeing the patients of thirty GPs (Lamb, 1977). In 1966 41% of GPs had either never or hardly ever met their district nurses (Hockey, 1966).

Hockey's study of six district nursing teams published in 1966 seems to be one of the few studies illuminating the work of DNs in the early years of the NHS. Her conclusions were that the DNs' skills were not used to their full potential and few DNs had auxiliary nurses to whom they could delegate basic work. Thus they were often involved in household chores, such as cooking and shopping when no-one else was available (Hockey, 1966).

2.3.3 Dying and primary care 1948 - 1967

1967 marks what is generally accepted as the beginning of modern palliative care (Clark, 1999b), with the opening of St Christopher's Hospice by (later Dame) Cicely Saunders. Loudon and Drury (1998) state 'unfortunately we know very little about the care of the dying in general practice before the 1960s, except that it was shrouded in silence... [and GPs]... did what they felt should be done on the basis of no

training other than what they might have picked up from their senior partners or other general practitioners' p121. Clark (1999b) moreover is forthright about care of the dying pre 1967, observing that in the early years of the NHS:

'there was to be little attention to medicine's 'failures', to those in their last illness whose time was short ...[and] no strategic or operational guidance on terminal care and no systematic commitment to the subject as a clinical issue' p227.

However, given the plight of general practice in these early years which was similarly ignored despite being the largest branch of medicine and the bedrock of the NHS, it would perhaps have been strange if attention to the dying patient had been any greater.

2.3.4 Medical attitudes and literature of terminal care 1948 - 1967

Medical interest in the care of the dying seems to have been extremely limited in the early days of the NHS, thus Clark comments:

'In the BMJ and the Lancet, medical comment on the dying throughout the 1950s tends mostly to the autobiographical and the quizzical' p232 (ibid).

Citing Hinton, Clark indicates that no systematic study of the experiences of the dying was conducted between a study by Osler in 1906 and a study by Exton-Smith (1961) of the elderly dying. Most medical writing was based on personal experience and anecdote.

Clark points to an issue of the Practitioner in 1948, devoted to the subject of death and containing an article, 'The care of the dying' by WN Leak MD.⁷ As Clark points out Leak indicates that the article is based on personal experience which is often 'fumbling with no one more experienced at hand to guide me' p87 (Leak, 1948). Clark (1999b) comments that Leak uses no references, which should be no great surprise, since at that time this was common practice even in the Lancet. Leak uses the prosaic style of the day, with comments belying the social attitudes of the medical profession. For example in a discussion about managing the scene after death he advises:

⁷ Leak's professional position is not revealed in the Practitioner article, although he writes from the perspective of a GP, for the GP, recounting his experiences of caring for the dying in their homes.

‘When one hysterical girl sets the rest “a-sighing and a-sobbing”, it is wise to put the brake on somehow, usually by giving one or two something definite to do, and by giving the ring leaders a good dose of barbiturate with a cup of tea. I find that seconal sodium seems to do better than other preparations at such times; it acts quickly and its bright red capsule appeals to the fairer sex’ p85 (Leak, 1948).

Arguably the article should be read understanding the dominant medical discourse, where the opinion of respected authorities judged in a strict hierarchy, anecdotes from practice and appeals to classical literature were the normal guiding principles.

Clark (1999b) suggests that in Leak’s article

‘The tone on matters of policy is fatalistic: “however desirable it may seem to some that all old people should obtain the best skill and care in their dying moments, it seems pretty clear that this will remain an ideal for a long time to come”’ (citing Leak) p231.

Conversely this could be seen as realistic, given the post war austerity, the focus of health policy on curative medicine and Leak’s fear of the effect of the new NHS on traditional doctor-patient values:

‘It is pathetic – and exacting – how eagerly dying people look forward to the visit of their doctor, even though there is nothing the doctor can do to assist them medically. In the new Health Service I expect that this side of medical practice will disappear with the older generation of practitioners. It will be dismissed as sentimental tosh. Yet it is the very essence of good general practice’ p83 (Leak, 1948).

The article does give advice for managing the terminally ill which although rudimentary would still be regarded as relatively sound: the importance of nursing care for bowels, incontinence and mouth care; he challenges the belief that morphine hastens death and asserts that test dosing enables it to be used without fear of overdosing; although no guidance on dosage is given. Furthermore, he highlights the need for an individual approach suggesting that it is the discerning physician who will tailor the medical approach to the patient sensitively.

Gavey (1952), a physician from the Westminster Hospital, gives more detail than Leak regarding the use of morphia which he advises to be given regularly 'unless the pain is paroxysmal' p22. His description of the use of other palliative drugs such as antiemetics is similarly sound and his essay is cited by Saunders (1958) in her first published paper and by Exton-Smith (1961) as a reason for him not needing to discuss palliative therapy in detail in his paper.

On the question of openness with the patient regarding a terminal diagnosis, Leak (1948) offers no clear guidance although he does advocate telling the patient or friend. However he advises against evading a patient's direct questioning suggesting that a straight reply is normally met by a patient's gratitude with the benefit that:

'It is vastly easier to manage the patient after such a simple and sincere acknowledgement of the fact' p83 (ibid).

The diversity of opinion at this time regarding the discussion of a terminal prognosis with the patient is illustrated in a 'Discussion on palliation in cancer' from the Section of Surgery of the Royal Society of Medicine (RSM) led by Gavey in 1955 (Gavey et al. 1955). Contributors are divided between advocating telling the truth, deliberately lying and taking a cautious line. Gavey himself felt that there was no place for a deliberate lie or for silence and recognised the burdens placed on the patient by a policy of not telling. In his 1952 essay Gavey's opinions are given more fully. He advises against the 'sudden announcement of the true nature of the disease' because of the distress this will cause, but 'a guarded diagnosis, slowly revealed enables a patient to prepare himself for a possible blow, retaining a hopeful attitude in the background' p 7 (Gavey, 1952).

By 1957 Gavey, speaking at the Section of General Practice at the RSM, is more forthright:

'I would say without hesitation after years of study of this problem that there is more to be gained than lost by adopting the attitude that enough should be said to satisfy those who wish to know the truth. Much depends of course upon the way and time of telling, but I have been astonished at the courage, determination and final resignation of so many patients and my admiration and thankfulness for their fortitude grow daily. The fact remains that there are still two attitudes to be

found among us. Those who tend to tell and those who tend not to tell. I feel that the tide is turning in favour of telling' p118 (Gibson and Gavey, 1958).

Medical writing in the 1940s and 1950s on terminal care is primitive by current thinking. Like much medical treatment of the time (Doll, 1998) terminal care was not based on rigorous evidence (by today's standards) and therapeutic options were limited; nonetheless the writing of Leak and Gavey seems to hold the seeds of therapeutic practice developed by Saunders and others from the early 1960s. Indeed Parkes in an interview acknowledged:

'I think that Elisabeth Kubler-Ross, Cicely Saunders and perhaps myself too, to some extent, although we're often seen as innovators, we were actually doing what the world was ready for' p32 (Clark et al. 2005).

From 1958 onward the prolific writing of Cicely Saunders began to appear (Clark, 1998). Her research, narrative insights and work in establishing St Christopher's hospice have reached almost legendary proportions, the story having been captured in many publications including Clark et al's. (2005) 'oral history project' and her own writing (Saunders, 2006; Saunders, 1996). Her important work developing the concept of total pain underlay the insistence that hospice care needed to embrace a multidisciplinary approach (Clark, 1999c).

Medical attitude towards the dying patient is an important issue relating to palliative care. However, the patient experience of dying in the community depends as much on social conditions and services available. Important work was undertaken in the 1950s in this area, which I shall briefly explore to illustrate the context of community care at that time.

2.3.5 Social conditions for terminal care 1948 - 1967

Two national studies commissioned by charities were conducted in the 1950s. The first from 1950 to 1952, by a joint committee of the Marie Curie Foundation and the Queen's Institute of District Nursing and the other by Dr HL Glyn Hughes for the Calouste Gulbenkian Foundation, published in 1960, give a graphic description of the plight of the dying in those early years of the NHS.

Marie Curie Memorial Foundation was established in 1948, taking as one of its principle objectives 'the provision of a welfare service to help domiciliary cancer

cases, as an ancillary to those services already provided by the National Health Service' p68 (Raven, 1990). Ronald Raven⁸, a surgeon who chaired the 'joint committee' describes how the study was designed to assess the plight of cancer patients and seek methods for their relief. Over 7000 cases were surveyed between January 1950 and April 1952, by DNs who had been approached through the local authority MOH, with a questionnaire designed to capture aspects of the social and clinical needs of cancer patients. The report probably reflected as much the state of elderly people living in appalling social conditions in post war Britain, often isolated and dependent on neighbours and friends and with seemingly little idea of their entitlement under the NHS or National Assistance Scheme (Clark, 1999b) as it did the plight of cancer patients specifically. Whilst the report suggested that complex cases would need institutional care.....

'....the provision of domiciliary nurses, especially to nurse patients during the night, was stressed. Many patients required help urgently at short notice and lack of it could cause much additional suffering for the patient and considerable anxiety for the family' p68 (Raven, 1990).

On the basis of the report the Marie Curie Memorial Foundation set up the first of a series of nursing homes for cancer patients in 1952, to provide continuing care for serious cases and to provide respite for patients and their families at times of crisis. In 1958, the Marie Curie Home Nursing Service was established with 26 nurses caring for 88 patients in the first year, expanding to care for more than 15,000 patients currently (MCCC, 2007).

Glyn Hughes' study was carried out between November 1957 and December 1958, through requesting information from all MOH, all senior administrative medical officers of regional hospital boards, voluntary organisations, religious orders, philanthropic organisations, service organisations, nursing bodies and almoners, including visits to 300 hospitals, homes and headquarters (Glyn Hughes, 1960).

His findings indicate that 40% died in NHS hospitals with 82.4% of the remainder, i.e. fractionally under 50%, at home. Whilst there was indication that home conditions were generally improving, concern regarding social changes such as the

⁸ Raven was deputy of the Marie Curie Foundation from 1951 and then chairman from 1960.

reduction in size of family potentially reducing the pool of carers available for the patient was expressed.

Institutional 'homes for the dying' mainly run by religious organisations with dedicated staff often had poor and cramped conditions, with beds close together, no curtains around the beds and no day rooms for ambulant patients. Nursing homes came in for particular criticism, with poor conditions and lack of standards in care and seemingly little local authorities could do to rectify the situation. GP cottage hospitals on the other hand were highly regarded for both clinical standards and pleasant environment for the dying patient.

Glyn Hughes' study gives some detail of the care provided by the primary care team. DNs were seen as being central to care but often overworked:

'Unable to pay sufficient visits to deal adequately with patients living alone, or to provide the necessary support for neighbours or relatives helping with the case. Although by no means all annual reports by medical officers of health comment on the adequacy or otherwise of home helps, general practitioners and councils of social service are emphatic that practically everywhere the numbers employed cannot meet the situation' p34 – 35 (ibid).

Lack of training in control of pain and insufficient use of controlled drugs by GPs, led Glyn Hughes to the recommendation that more attention needed to be given to the training of medical students in care of the dying.

Since it was recognised that most patients wanted to stay at home, better coordination of services between local authorities, local hospitals, medical committees and local voluntary organisations through the setting up of 'area committees' was recommended along with urgent attention to the employment of suitable staff to supplement the over stretched DN services. It was suggested that 'female relations' p57 could be compensated for loss of income when providing full time care for a dying relative. However, it also needed to be recognised that hospital admission would be necessary for some patients and 'planning should allow for a proportion of beds to be set aside for this purpose' p61.

In 1965 Wilkes, a GP in Derbyshire and later founder and medical director of St Lukes Hospice Sheffield (1971 – 1984) and professor of general practice at Sheffield

University (1971 – 1984), published a paper which he identified was ‘maybe the first of its kind, for it reports the findings of a local survey among general practitioners of cancer patients dying at home’ p799 (Wilkes, 1965). The study had a high response rate of 91% and included details of 374 patients either at home or in a nursing home, estimated to represent 20% of cancer home deaths in the area.

The important role of DNs was again demonstrated with input reported for 63% of patients. Seventy five percent of patients were reported to have no idea of their diagnosis, suggesting that either patients had not been told or GPs were unaware of their knowledge. Hospital admission was reported as difficult to obtain for some patients; in addition lack of caring services in the community were noted with almost 10% of patients reported as having insufficient access to night nurses.

2.3.6 Discussion of emergent care of the dying 1948 – 1967

Primary care and care of the dying for almost the first two decades of the NHS received scant interest or development in terms of strategic policy by the government or priority of medical bodies. NHS energies were directed almost entirely towards cure and rehabilitation within acute hospitals. Championing the cause for primary and terminal care was left to a few pioneering GPs in establishing the RCGP for the former, and to charities for the latter.

Whilst practice seems to have been poor in both areas, the seeds of the development which rapidly emerged in the 1960s and beyond are evident in a few studies and writings in the 1950s and in the reflections of practitioners writing about those times. The GP charter introduced an atmosphere of hope and expectancy as the working conditions of general practice improved and academic departments enabled the distinctive discipline of general practice and primary care to develop (Morrell, 1998). Similarly with the hospice movement a new more positive discourse around care of the dying emerged such that:

‘An active rather than a passive approach to the care of the dying was promoted with increasing vigour. Within this the fatalistic resignation of the doctor that “there is no more we can do” was supplanted by the determination to find new ways of doing everything’ p242 (Clark, 1999b).

Two personalities of significance stand out as heralding a new era in this period, Michael Balint and Cicely Saunders. Both of them realised the importance of listening to the patient, developing good communication skills and recognising symptoms as representing an amalgam of psychological and social distress as well as physical illness which needed a holistic approach to management. Saunders developed the concept of total pain (Clark, 1999c) and Balint (1957) encouraged a reframing of the patient with a ‘trivial complaint’ as potentially presenting a complex psychosocial issue.

Interestingly however, it seems that there was little if any formal link between Saunders and Balint. I am not aware of Saunders making any reference to him in her writing, either her papers or her letters.⁹ Whilst there was cross-over between general practice and hospice work, with many of the original pioneers in the hospice movement being GPs (Clark et al. 2005), these two new disciplines in medicine seem to have developed in parallel over the next two decades.

Clark (1999b) suggests that in the early 1960s the division between palliative care and geriatrics was set, with the former mainly for younger patients suffering from cancer, and the latter concerned with the ‘elderly in general including their dying’ p235 (ibid). In a letter cited by Clark between Saunders and Exton-Smith dated 2nd September 1960, and presented by Clark in his collection of Saunders’ letters, Saunders concurs:

‘Your experience about the pain of your patients with cancer does bear out mine, in that it is not the older age group who get severe pain’ p38 (Clark, 2002b).

For primary care, there has never been the luxury of patient selection and the issue of care for the dying elderly and for patients with non cancer diagnoses, in which the elderly are ‘over-represented’ (Addington-Hall et al. 1998b) is of importance (Barclay, 2001). The division between palliative care and geriatrics may have profoundly influenced the relationship between primary and specialist palliative care, which has been often been one of ambivalence (Sibbald and Simpson, 1991), sometimes bordering on outright hostility (Aldridge, 1987; Fordham et al. 1998).

⁹ Also despite discussions with Dr Richard Hillier, Dr Jo Hockley and Professor Jane Seymour I have failed to expose a link between the two.

The relationship between general practice and the emerging hospice movement is arguably of significance. Clark concludes his review of terminal care in the early NHS thus:

‘In the period from 1948 to 1967 terminal care under the NHS had experienced a difficult beginning, which would make all the more remarkable the expansionist years which were to follow’ p244 (Clark, 1999b).

Undoubtedly many social factors account for this, along with the highly charismatic work of Cicely Saunders herself. However, it may be that the conjunction with an emergent, newly defined and increasingly confident discipline of general practice providing as it did young, visionary GPs to join in the pioneering work in hospice care throughout the UK (Clark et al. 2005) was important, without which such expansionist years might not have been so remarkable.

2.4 1968 – 1987: Emergence of primary and community palliative care

The twenty years between 1968 and 1987 saw significant development in both general practice and palliative care. The period starts with the GP charter and the opening of St Christopher’s and closes with the heralding of the 1990 contract introduced by the Thatcher government (Rivett, 1997), achievement of speciality status for palliative medicine (Hillier, 1988) and the first NHS strategic approach to policy on terminal care (Clark and Seymour, 1999). For DNs the opportunity to be attached to practices along with the nascent concept of the primary care team in the late 1960s led to changes in working conditions and practices for nurses in the community, whilst the introduction of Project 2000 in 1988 making nursing into a graduate profession and leading to the rise of the community nurse specialist marked the end of this period (Rivett, 1997).

2.4.1 Primary care 1968 - 1987

Bosanquet and Salisbury (1998) assert that ‘the emerging culture of general practice, evolving social expectations and political imperatives’ p51 after 1967 enabled many changes to occur within general practice and led to the emergence of the concept of primary care as the integration of medical and nursing services in the community.

Some important changes and trends apparent within general practice at this time were noted in two surveys of general practice in 1964 and 1977 (Cartwright and

Anderson, 1981). During this period the proportion of doctors working on their own fell to 12%, with only 4% of GPs aged 40 years or under doing so.¹⁰ Consultation rates by general practitioners remained relatively stable, but the proportion of home visits to surgery consultations dropped significantly, along with patient satisfaction regarding the availability of home visiting. Practices operating an appointment system increased from 15% to 75%. The regular or occasional use of out of hours deputising services by GPs increased from 9% to 44%. Patient expectations also seemed to have changed with fewer patients being critical of consultations ending without a prescription and significantly more patients reporting that GPs were more prepared to give explanations concerning treatment plans; although levels of patient satisfaction with this aspect did not improve. There was evidence that GPs who had undergone vocational training were considered easier to talk to than those who had not, although there was no such difference between RCGP members and non-members. Younger patients however were more likely to complain about their GP in 1977 than in 1964.

Thus there was evidence that practice improved generally after the GP charter, whilst patient satisfaction had remained rather static, arguably due to increased knowledge and expectations amongst patients (Cartwright and Anderson, 1981). The authors thought that the reductions in home visiting could only partly be seen as a result of increased patient mobility in 1977, whilst Pereira Gray in his 1978 William Pickles Lecture to the RCGP expressed concern about the detrimental effect reduced visiting would have on the doctor patient relationship (Gray, 1978).

2.4.1.1 Developing the primary health care team 1968 - 1987

One of the major developments in primary care from the 1960s onward was the development of DN attachment to general practice. Armstrong (1983) indicates that until 1960 there were 'less than 20 attached health visitors, district nurses and midwives in the whole country' (p83), whilst by 1969 25% of DNs worked in attachment schemes. The 1966 GP charter also provided the conditions for direct practice employment of nurses through reimbursement of staff costs to GPs

¹⁰ For this reason Cartwright predicted that single handed practice would die out, however this has not transpired with at least 6% of GPs being single handed in 2005
http://www.rcgp.org.uk/information_services/information_services_home/is_publications/information_sheets.aspx (Accessed 20/07/06).

(Webster, 1998). However as Drury (1967) commented at the time, little concept of how primary care teams should work existed:

‘Agreement on the constitution and field work of such a team is a problem that has not yet been grappled with, and our ideas on these are too much conditioned by existing practices’ p823.

Drury feared that many GPs had little understanding of the professional skills which DNs possessed which could lead to a frustration of the ideal of ‘complete integration of nursing and medical services within family practice’ p825 (ibid). Concepts and practical aspects of multidisciplinary working are still problematic, especially in primary palliative care. I will discuss this issue in Section 2.8.

Despite concerns regarding the availability of nurses to work in primary care (Drury, 1967) there was rapid growth in this area, so that by 1977 84% of general practices worked with nurses as part of the team (Cartwright and Anderson, 1981). Whilst some of these were practice nurses directly employed by the GP and some were DNs employed by the health authority, differentiation between them is difficult, since there was overlap in their duties, with some DNs doing work inside the surgery and some practice nurses performing home visits. Patterns of practice also emerged, with doctors with attached nurses more likely to have employed nurses also and only half of single handed practices having attached or employed nurses; the proportion falling with practice size so that only 4% of practices with at least five partners had none.

The relationship between having a nurse attached to the practice and a commitment to a team approach in primary care on one hand and the principle of family practice on the other remained unclear at this time. When asked by Cartwright and Anderson whether there should be more emphasis on team working in the future, equal numbers of GPs with and without nurses working in their practice thought that there should be. However, paradoxically GPs ‘*without* (emphasis original) a nurse attached more importance to family care, 41% considering it as very important compared with 24% of doctors working in a practice with a practice nurse’ p92 (ibid).

2.4.2 Community palliative care 1968 – 1987

In 1969 two years following its opening, St Christopher’s Hospice established a home care outreach service ‘which would take hospice skills and philosophy into the

wider community' p75 (Clark and Seymour, 1999). There followed a period of rapid growth of hospice inpatient, home care and day care over the next twenty years. These often grew as a result of local initiatives and charitable fund raising, resulting in a wide variation in type and availability of service. In 1980 Lunt and Hillier conducted a national survey of palliative care services, finding that there were 58 inpatient hospices, 32 home care and 8 hospital support teams. Whilst a quarter of hospice inpatient units had opened in the previous 2 years, the number of home care teams had doubled in that time (Lunt and Hillier, 1981). Most of the expansion of home care was the result of the establishment of the Macmillan nursing scheme in 1975 by the National Society for Cancer Relief (NSCR) – now Macmillan Cancer Support (MCS). Whilst by 1978 only 10 nurses had been appointed, rapid expansion was made possible from 1980 onwards through a £2.5 million investment in the project (MCS, 2006). Repeating the survey in 1984, 87 home care teams had been established 72% funded by NSCR (Lunt, 1985).

Publications had also started to appear describing the 'hospice approach', e.g. 'The management of terminal disease' edited by Saunders (1978). Robert Twycross, who had joined St Christopher's as a research fellow in 1971 (Clark et al. 2005) and has written prolifically on palliative care, in 1980 wrote of the hospice approach to terminal care. The style is direct and gone is the prosaic writing of the 1950s:

'Cardiac resuscitation, artificial respiration, intravenous infusions, nasogastric tubes, and antibiotics are all primarily supportive measures for use in acute or acute-on-chronic illnesses to assist a patient through the initial period towards recovery of health. To use such measures in the terminally ill, with no expectancy of a return to health, is generally inappropriate and is, therefore, bad medicine by definition. It is, however, not a question of 'to treat or not to treat?' but, of what is appropriate treatment from a biological point of view in the light of the patient's personal and social circumstances. Medical care is, in fact, a continuum ranging from cure at one end to symptom control at the other. When cure is no longer possible palliation should be considered; when palliation is no longer possible, the emphasis moves to symptom control as an end in itself' p477 (Twycross, 1980).

In the late 1970s and early 1980s discussions around the emphasis which should be taken in the delivery of palliative care emerge. Whilst all seemed to agree that it was necessary to provide palliative care services in specialist inpatient units, hospitals and the community, differences of opinion regarding which type of service was more effective or preferable are apparent. These opinions along with realism concerning limited resources influenced policy suggestions.

Twycross (1980) suggested the preferred model should be one of continuing care, which...

‘...comprises inpatient facility, outpatient clinic, day unit, domiciliary consultation, home care, consultation service for other hospital departments, and bereavement visits’ p481 (ibid).

This vision was modelled on the service at the ‘Montefiore Hospital’ in New York and as such suggested that for patients receiving the service, total care was taken over by the hospice or palliative care team. As a realist however, Twycross accepted that such a model was not universally feasible, accepting that shared care would be necessary, although he did not specify the form he thought this should take.

The ‘Report of the Working Group on Terminal Care’ chaired by Wilkes and commonly referred to as ‘The Wilkes Report’, took a different stance. They suggested that a major expansion of inpatient units was not required and that development of community care, with the DN and GP as central should be the priority for social and professional reasons:

‘Some patients and their families find the idea of admission to a specialist terminal care unit distressing. Indeed, it might be argued that there was something unhealthy with any society which felt the need to hide dying patients away in separate institutions. From a professional viewpoint there are also some disadvantages in detaching terminal care from other aspects of care. Both hospital staff and the primary care team can feel a commitment to care for their own patients through their last illness and consider it a rewarding experience’ p468 (Working Group on Terminal Care, 1980).

The report concluded that specialist inpatient units should be restricted to larger towns and cities, because travel into such centres would not be such an issue for

relatives; also smaller families and more patients living on their own, relative to other areas, would make such facilities particularly appropriate. These units it was suggested should also fulfil a research and teaching function as well as developing new approaches to symptom control. Since palliative care should be delivered by all clinicians, the working group reiterated the importance of undergraduate medical education in care of the dying, highlighted by Glyn Hughes two decades earlier (Glyn Hughes, 1960).

A similar approach is also taken by Lunt and Hillier (1981); conversely Parkes takes a different view. Based on consecutive surveys of surviving spouses in the St Christopher's area, 1967 – 69 (Parkes, 1978) and 1977 – 79 (Parkes, 1985), which reported that pain control in the community was inferior to that achieved in both hospice and hospital, Parkes argued that good palliative care in the community may be elusive and stressed the importance of investment into new inpatient units (Parkes, 1985).

This difference in emphasis may in part arise from the backgrounds of the protagonists. Wilkes and Hillier were from general practice, Twycross was from hospital medicine and a self confessed believer in the NHS and social medicine, thus favouring an integrated specialist approach. Parkes was one of Saunders' earliest collaborators, a psychiatrist who had witness the full struggle to establish St Christopher's (Clark et al. 2005).

What was also starting to emerge in the literature was a realisation that there are conflicting issues: patient and carer wishes; effective symptom control and patient choice which could not be easily balanced. Hinton, also a psychiatrist and an early writer and researcher in terminal care, observes the difficulty in conducting comparative research and the possible effect on carers of different contexts.

‘Those looking after the patient at home spoke more readily of the patient's anxieties and demands - their quirks and weaknesses as well as their courage. Perhaps chance produced a less stable group at home, but more probably husbands and wives were shown more of the patients' personal reactions and frailties. In contrast, relatives' comments on the usually welcome tranquillity of those dying as inpatients sometimes had a slightly disconcerting obituary glaze

which obscured personal foibles and even the texture of human character. Calm is not the only appropriate emotion for the dying' p32 (Hinton, 1979).

Thus, by the early 1980s, questions regarding both the most appropriate form of palliative care provision and the effective evaluation of palliative care services had emerged. Both of these issues have not been fully resolved and continue to be debated more than a quarter of a century later.

2.4.2.1 Palliative care in primary care 1968 – 1987

In the early 1970s, further studies of palliative care by GPs began to emerge. Dewi Rees, a GP in mid-Wales and later medical director of St Mary's Hospice, Birmingham, devised a tool for nurses to score distress in dying patients. This allowed comparisons to be made between patients dying in an acute hospital, community and GP cottage hospital (Dewi Rees, 1972). In this study more than 52% of the deaths occurred in a GP hospital, 14% within an acute hospital and 26% occurring at home (the other 8% dying in a 'chronic sick unit'). The low proportion of deaths at home¹¹ Dewi Rees suggests was due to the availability of a cottage hospital which enabled the patient, family and GP greater choice in site of care. Patients at home were less likely to suffer 'distress of dying' in comparison to those in hospital, unlike Parkes' study (1978) also undertaken the same year. However, over half the patients, in any setting, suffered from pain leading Dewi Rees to reflect that the study...

'...made me realize the large extent to which the terminally ill under my care were receiving inadequate relief from their sufferings. This finding was particularly important as I had previously considered my management to be at least adequate' p107 (Dewi Rees, 1972).

Interpreting Dewi-Rees' results is problematic. Only 50 cases are considered across all sites and the reliability and validity of the tool he used is not reported. It is interesting however, that he did report better pain control in the community than Parkes, which could reflect the difference between South East London and a rural community in mid-Wales. However, Parkes surveyed bereaved spouses who might

¹¹ For the same period Cartwright et al.'s (1973) national study suggests a rate of 42%

tend to over-report pain whilst Dewi-Rees's tool was used by nurses who might tend to under-report pain (Grande et al. 1997a).

Home death rates in rural areas also differed remarkably. A study of community palliative care in Cumbria in 1989 reported an achievement of 83/157 (53%) home death rate (by this time national home death rate had fallen below 30%), although high levels of unmet need and carer stress were still apparent (Herd, 1990). Herd reflects that high levels of home death could be related to strong community cohesion in this area and high levels of social stability (e.g. no patients were divorced or separated).

Papers published by GPs in the 1970s and 1980s illustrate the interest and commitment of GPs to this area of primary care practice. Using a variety of methods these illustrate the wide variability of practice and experience in community palliative care. Some highlight the variability in levels of awareness amongst patients and communication by GPs at this time. Reilly and Patten compared the views of relatives and carers for 118 patients who died in the Belfast area in 1979. Only 8% of GPs had discussed the terminal prognosis with patients even though for 80% of patients, GPs reported that they had known the patient had been dying (Reilly and Patten, 1981). In contrast Barritt, (1984) describing all 31 deaths within a 3800 patient, 2 doctor practice over one year reports discussing dying with 5 out of 6 patients who died at home with a known terminal phase. In a 1977 study of 97 patients dying in Southampton, patients and relatives (or ward nurses if the patient was in hospital) were interviewed. Interviewers estimated that 48% of patients knew their diagnosis and prognosis, but only 30% of relatives or staff thought they did (Woodbine, 1982).

A survey of GPs, community and hospital nurses and relatives for 262 deaths in Sheffield was reported in 1984. Variable quality of care was evident and whilst 24% of relatives were grateful to their GP, 37% were critical. The highest level of criticism was related to poor out of hours care, especially with the use of a deputising service. Forty four percent of community nurses also reported that the patient's quality of life had been poor or very poor (Wilkes, 1984). Evidence emerged that the practice of giving regular analgesics to patients in pain was sometimes not followed, with a reluctance to prescribe strong opioids for severe pain. Woodbine (1982) found

that of 16 patients prescribed strong opioids only 4 were taking these regularly and that of 29 patients with moderate or severe pain, only 4 were receiving strong opioids.

The complexities of achieving good symptom control were highlighted by Reilly and Patten (1981) who remarked:

‘The therapeutic task was one of considerable complexity because of the range of symptoms suffered by any one patient, with rapid alteration in symptom pattern, and because of the wide variation in symptoms between patients with the same terminal illness’ p537.

Barritt (1984) also questioned the validity of using the proportion of home deaths as a proxy for good palliative care, finding that of the 25 deaths in his practice which were not sudden, 11 had been in hospital during admission for an acute illness or for investigation of a chronic illness. Of the 14 patients with a terminal diagnosis, the practice had cared for all but three during their terminal phase; but five of the remaining eleven had been admitted to hospital because of heavy nursing needs, relatives being unable to cope or unwilling to care or worried about dealing with a home death. Barritt’s study resulted in the establishment of a local charitable home nursing service to provide additional help for carers of terminally ill patients.

2.4.2.2 District nurses and palliative care 1968 - 1987

The 1969 Cartwright et al. (1973) and 1987 Seale and Cartwright (1994) studies present a very useful comparison of the change in DN services over the 18 year period, during which time the pattern of DN involvement with patients in their last year of life had changed, whilst the proportion of patients receiving DN services had not. In 1987 DNs were reported as being involved earlier in the patients’ illness but providing fewer daily visits when they were involved. Seventy five percent of DNs in both studies felt that the service they provided was adequate, however 48% DNs reported GPs referred patients too late in 1987 in comparison to 16% in 1969 (Seale, 1992). Seale suggests that earlier involvement might indicate an expanding role for DNs in terminal care, but offers no explanation for fewer visits. The introduction of syringe drivers to palliative care practice in the 1980s which was described by Doyle (1987) as having ‘revolutionised’ palliative care in the community, could have been

one factor which affected this. Before this time medication needed to be given by rectal route or by regular injection for patients who could not swallow (Copperman, 1983), which may well have resulted in more frequent DN visits.

In reviewing community nursing services in palliative care Bergen (1991) found that there was little high quality research which had been reported between 1980 and 1990 with most studies being confined to descriptions of services offered. Most of these studies investigated the role of DNs as part of larger surveys.¹²

Reilly and Patten (1981) found that three quarters of 118 terminally ill patients in their Belfast study received district nursing support, most typically 2 visits per day, although they make no distinction between cancer and non cancer patients in terms of the district nursing input they received. They comment that a 'few' relatives indicated that arranging district nurse care was difficult, whilst the GP seemed unaware of this. Woodbine (1982) comments that in a questionnaire survey of 97 dying patients and their relatives in Southampton, the most common visitors in the community were the DN and GP, although the number of patients receiving DN services is not reported; however 12% of relatives reported that night nursing services were insufficient for their needs. Wilkes (1984) also gives no indication of the proportion of patients receiving district nursing services in his sample of 262 bereaved carers in Sheffield (unlike his 1965 study). Eighty five percent of relatives agreed with the decision to not involve the DN if this had been the case. However, of those who had received the service, 26% thought the DN visited too infrequently.

2.4.2.3 Community specialist nursing 1968 - 1987

The availability of community specialist nursing services in this period varied widely. Few Macmillan nursing services offered 'hands on care', the majority being advisory, whilst services linked to hospices could provide a range of care (Bergen, 1991). Few studies of specialist community services at that time were reported, most being confined to local reports or unpublished theses (Bergen, 1992). The national surveys of Lunt and Hillier (1981) and Lunt (1985) highlighted the rapid rise in numbers of Macmillan nursing teams from 1975.

¹² Seale and Cartwrights 1987 study had not been published when Bergen wrote her review.

Doyle (1982) reported on an evaluation of an early Macmillan nursing service in Edinburgh. The service was able to highlight and address areas of deficiency in the care of terminally ill cancer patients and 41% of patients referred to the service remained at home until they died. Although Doyle compares this favourably to the national 30% home death rate, the local death rate was not stated, neither is it reported whether the service improved home death rate for the group of patients who received it.

2.4.3 Summary

The period 1968 – 1987 produced a rapid expansion in all forms of palliative care service provision, including community services, but most of this occurred in a rather haphazard manner. Most of the studies into community palliative care delivered by GPs and DNs in this period are descriptive and are locally based, making it difficult to judge whether the conditions reported were generally those found in the UK. In addition different methods used make comparison between studies difficult. The studies do however seem to point to a high degree of variability in the quality of care patients received and reveal high levels of unmet need.

Whilst community specialist services rapidly emerged during this time, little has been reported concerning them, except that they were highly varied in their configuration and roles. Macmillan nurses, later to become palliative care clinical nurse specialists, were notably providing an advisory service.

Differences of approach arose between protagonists of palliative care, with those from a primary care background seemingly promoting a community services in which GPs and DNs would be central to provision. This period also ended with the somewhat contentious formalization of palliative medicine as a specialty. This will be discussed in this next section.

2.4.4 General practice and the emergence of specialist palliative medicine

The ‘Statement by the working party of the second European conference on the teaching of general practice’ and endorsed by the RCGP in 1977, highlighted terminal care as an important aspect of general practice (RCGP, 1977), as did the 1980 ‘Wilkes report’ (Working Group on Terminal Care, 1980). In an editorial in the *Journal of the RCGP* accompanying the Wilkes report a warning note is sounded:

‘As general practitioners we must be grateful for these achievements [in care of the dying] and respect and support these centres of excellence [hospices]. We must be wary however, that the care of the dying does not gain the eccentric status of a specialty. It is part of general practice and we can and must be worthy of it’ p451 (Anonymous, 1980).

However, a study in London indicated that GPs appreciated specialist support from palliative medicine, with 107/191 (56%) agreeing that specialist domiciliary medical support would be very helpful or essential and only 11% indicating it would not be helpful (Haines and Boroff, 1986).

In 1987, the speciality of palliative medicine was established. Whilst a joint committee on palliative medicine had been established between the RCGP and the Royal College of Physicians (RCP) it was the latter that became the host body for the speciality (Hillier, 1988). Hence palliative medicine from that time has been considered a medical sub-speciality. Palliative medicine established a journal *Palliative Medicine* in 1986 and developed its own professional body ‘The Association for Palliative Medicine’ (APM) although a specialist training programme for accreditation did not emerge until 1997. In some ways it seems a paradox that palliative medicine is a medical sub-speciality, given palliative care’s close links with general practice in the first two decades since its inception. Some tried to argue for the new speciality being located within the RCGP (personal communication Richard Hillier), however, given the ambivalence in general practice towards specialism arising from the implied devaluation of generalism, it is perhaps not surprising that the RCGP was not in a position to accept palliative medicine, in contrast to the RCP.

Palliative medicine as a speciality has been defined as

‘The study and management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is the quality of life’ p3 (Doyle et al. 1998).

This immediately casts into doubt its definition as a sub-specialty since unlike medical sub-specialisms, palliative medicine, relates to a stage of a patient’s condition rather than a particular pathology (Doyle, 1993). In some ways therefore it might be seen as a ‘generalism’ applied to the end of life rather than a ‘specialism.’

Kearney (1992) argued against palliative medicine becoming a specialty of ‘symptomatology’ following too closely the medical model and that it should embrace a model which recognises the need for healing at a deeper level.

The essence of palliative medicine is, as Clark (2002a) suggests, difficult even for its practitioners to define. Drawing on ideas from general practice (Mathers and Rowland, 1997) he suggests that it is a post-modern specialty which ‘opens up a space somewhere between the hope of cure and the acceptance of death’ p907 (Clark, 2002a). Although this leads us to the territory in which palliative medicine practices it does not clarify the nature of the speciality in terms of its underlying principles of practice, neither does it provide a philosophical basis for an evidence base. General practice underwent a process of self definition in the 1960s (McWhinney, 1966); it is remarkable that palliative medicine has not done the same. Perhaps it is because being a medical sub-specialty it has a niche in which to reside and palliative medicine does not occupy the position of general practice of the early 1960s when it was said to have ‘fallen off the ladder’ p177 (Mathers and Rowland, 1997).

2.5 1988 to the present: Community palliative care and NHS policy.

The third phase I will describe in the development of community palliative care begins in 1988. The previous year, palliative medicine had been established and also the Department of Health had circulated the first national directive for terminal care in the NHS to all health authorities. District health authorities were instructed to take the lead in developing a strategy for the care of terminally ill patients, working in partnership with voluntary organisations and local authorities.¹³ Needs assessments were to be made to determine service needs, public preferences and staff training needs (Clark and Seymour, 1999). This represented the first in a series of policy documents, national strategies, NHS directives and reports which have surfaced frequently since that time (see Box 2-1).

¹³ In the 1974 reorganisation of the NHS, local authorities lost control of community services to District Health Authorities, but retained responsibility for social service.

- 1987 Palliative Medicine becomes a medical sub-speciality of the RCP.
Health Authorities mandated to develop terminal care policies.
- 1988 Government acceptance of UKCC 'Project 2000' proposals.
- 1989 White Paper: *Working for patients* (NHS Reforms).
- 1990 NHS and Community Care Act - GP Fundholding established.
Government commitment to fund hospices 50:50 (cf charitable funding).
- 1991 National Council for Hospice and Specialist Palliative Care formed.
- 1992 Expert committee report: *Principles and provision of palliative care*.
- 1995 Commission Cancer Services: Report of Expert Advisory Group (Calman-Hine Report).
GP out of hours arrangements change: Co-operatives form.
- 1996 EL(96)85 A Policy Framework for Commissioning Cancer Services:
Palliative Care Services.
- 1997 New Labour Government elected.
White Paper: *The New NHS: Modern and Dependable*.
- 1998 Primary Care Groups responsible for commissioning services.
- 2000 White Paper: *NHS Cancer Plan – Networks established*.
National Service Framework for Coronary Heart Disease.
- 2001 National Service Framework for Older People.
- 2002 NHS re-organisation: PCTs established, Strategic Health Authorities.
- 2003 White paper: *Building on the best: choice, responsiveness and equity in the NHS*.
- 2004 NICE Guidance on cancer services: *improving supportive and palliative care for adults*.
NHS End of Life Care Programme established
- 2005 National Service Framework for Long Term Conditions
- 2006 White Paper: *Our Health, our care, our say: A new direction for community services*.

Box 2-1 Policies and reforms of significance to community palliative care

The late 1980s and early 1990s saw a dramatic change in the organisational arrangements for medicine and health care. Most notable was the 1990 NHS and Community Care Act, which introduced the 'internal market' to the NHS. Concerns

over the viability of funding a state run health service and the drive to increase efficiency, combined with political ideology were the drivers of the reforms (Rivett, 1997). With them came the introduction of GP fund-holding where practices held budgets for commissioning certain aspects of secondary care, with the rationale that GPs were in a position to know their patients' needs more than health authorities or hospitals. Hospitals and community services could also apply to become semi-autonomous NHS trusts, managing their own budgets and negotiating contracts with fundholding GPs and with district health authorities which commissioned on behalf of non-fundholding GPs.

Changes in the organisational structure of the NHS were accompanied by changes within the nursing profession with the development of the role of clinical nurse specialist (CNS) which included the evolution of the Macmillan nurse into a palliative care CNS. Aspirations to transform nursing into a graduate profession through Project 2000 which were accepted by the government in 1988, combined with the aim for increased efficiency (Rivett, 1997) and finally the need to reduce junior doctors hours (Salvage, 1995) were arguably three drivers for this. The broadening of nursing roles since these times has led to the extension of the concepts of multidisciplinary working (Nolan, 1995) as discussed in Section 2.8 (page 86).

As palliative care became incorporated within the NHS and consumer opinions became an increasingly important factor to consider, e.g. through the 'Patient Charter' in 1991 (Rivett, 1997), concerns about terminally ill patients not being able to achieve their aim of a home death became prominent and subject to several studies (e.g. Karlsen and Addington-Hall, 1998; Townsend et al. 1990). Typically, studies found that whilst at least half of patients expressing a preference would choose to die at home, only around half of these achieved their aims, with most deaths occurring in hospitals. Drawing on these Thorpe (1993), reviewing community palliative care, described two paradoxes: 'most dying people would prefer to remain at home but most of them die in institutions' and 'most of the final year is spent at home but most people are admitted to hospital to die' p916. (I will discuss this issue at length in Chapter-3).

Palliative care and the role of primary care in its delivery began to be highlighted in reports, policy documents and directives from the Department of Health in the 1990s.

In 1992, the 'Report of the Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee: The principles and provision of palliative care,' made two significant recommendations: firstly, that palliative care be extended to groups other than those with cancer and secondly, that it should be provided in all health care settings rather than being confined to hospices (DH, 1992). These principles were adopted and have remained central to policy since that time; for instance the 1996 NHS Executive directive 'EL(96)85' mandated health authorities to develop commissioning strategies for palliative care and stressed the entitlement of patients to access to 24 hour specialist palliative care irrespective of diagnosis (DH, 1996). More recently the National Service Frameworks for chronic disease, announced in the NHS plan (DH, 2000c) (Box 2-1), the 2003 White Paper on choice in the NHS (DH, 2003), and finally the White Paper on community health care 'Our health, our care, our say' (DH, 2006a) have continued to highlight this overall policy. However, the implementation of systems and services to fulfil these aspirations still remains patchy (House of Commons Health Select Committee, 2004).

Palliative care has also been strengthened as an important aspect of cancer care. The Calman-Hine report of 1995 (DH, 1995) highlighted the importance of integrating all cancer services, including palliative care and stressed the important role of primary care in the care of cancer patients, citing the need for all practitioners including GPs and DNs to adopt a 'palliative care approach' (NCPC, 1995). The NHS Cancer Plan developed and formalised many of the recommendations of the Calman-Hine report particularly the need for multidisciplinary and cross institutional working with the establishment of cancer networks, with parallel palliative care strategy groups charged with integrating regional palliative care provision and developing palliative care strategy (DH, 2000b). The 'Guidance on cancer services: improving supportive and palliative care for adults' produced by the National Institute for Health and Clinical Excellence (NICE, 2004) is now the central 'evidence based' document for the delivery of cancer palliative care services, describing specifically the role of primary as well as specialist palliative care teams.

Recent service developments include the 2004 End of Life Care Programme (NHS, 2004); the White Paper on community services, advocating 'end of life care

networks' which aim to enhance co-operation and co-ordination between health and social care services and to have representation from other bodies such as ambulance trusts (DH 2006a); and a national strategy for end of life care (DH 2006b). These were discussed briefly in Chapter-1 (Section 1.3 page 23) and the implications of these developments will be explored in Chapter-7 (Section 7.3.3 page 290).

2.6 Postscript to the historical review

This brief overview of the history of primary and palliative care as they have developed in the UK over the last 60 years has illustrated the complex and evolving relationships which have strongly influenced the emergence of palliative care as it is currently practiced in the community. Primary care and specialist palliative care share much in common as is evident from their history. Many in primary care have developed an interest in palliative care either as part of their practice as primary care professionals, or have moved from primary into palliative care. According to 2005 data, 139/320 (43%) of consultants in palliative medicine hold the MRCP qualification (APM, 2005) and many palliative care CNSs have a background in district nursing (Webber, 1994). However, evidence also exists of tensions between the two disciplines both at an organisational level, for example the attitude of the RCGP to palliative care as a specialty and at the practitioner level (e.g. Fordham et al. 1998; Higginson, 1998). The reasons for this are in themselves complex. General practice has welcomed the emergence of palliative care but has been wary of a specialism encroaching into the traditional area of practice of the generalist (Charlton, 1997; Pugsley and Pardoe, 1986). This is arguably part of a wider tension between the generalist and specialist (Willis, 1995) which has existed throughout the period considered, but which has its roots much earlier in the pre-modern division between physicians (academics and university trained) and apothecaries (whose society was part of the grocer's guild) and who were the forerunners to GPs in the 19th century (Porter, 1997).

Whilst the development of strategy is a vital component in delivering coherent and effective services, it is no less vital to appreciate that the development of services and professional practice is contingent on complex historical factors. Examining current issues relating to the delivery of palliative care is therefore aided by an appreciation of the complex interrelationships of national health policy, the positions taken by

official professional bodies and relationships between practitioners in the clinical arena, all of which have emerged historically. I will now turn to a detailed analysis of the current role of GPs, DNs and palliative care CNSs in delivering community palliative care, followed by an examination of issues related to multidisciplinary working in palliative care.

2.7 Present day community palliative care: key roles and relationships

2.7.1 General practitioners

GPs have been central to the provision of care for dying patients since the inception of the NHS. Much has changed in the GP's role, with the emphasis now on the primary health care team rather than the individual GP and with some of the work in community care being taken on by community specialist and intermediate care services. For example community matrons are now taking a role in chronic disease management (Murphy, 2004) and patients with heart failure might be monitored in the community by clinical nurse specialists working with cardiologists from secondary care (Stewart and McMurray, 2002). Whilst DNs and palliative care CNSs have taken on an increasingly important role in palliative care, GPs are contractually obliged to remain involved in the delivery of terminal care¹⁴ which was included as an 'essential service' in the 2003 GP contract (BMA, 2003).

Since patients spend the majority of their last year of life at home (Seale and Cartwright, 1994) and GPs have a contractual obligation to care for terminally ill patients, they will arguably have a substantial role in palliative care. Some discussion in the literature has highlighted the central role of GPs in providing end of life care for all patients irrespective of diagnosis (Charlton, 1995; Barclay, 2001; Peppiatt, 1998) however, few studies have systematically examined the views of individual GPs and those that have, show a range of attitudes. One interview study reported that GPs cited palliative care as clinically important and professionally satisfying; an area in which they saw themselves as co-ordinators of care, working closely with DNs to deliver a multidisciplinary service, stressing the importance of offering care to people with any chronic and life threatening illness and providing bereavement care

¹⁴ I think that use of the 'terminal care' here illustrates the problems with definitions highlighted in Section 1.2. I do not think the developers of the contract envisaged GPs only being involved in the last days of life.

(Field, 1998). This study sampled 25 GPs who had qualified from the same academic year of the same medical school and thus may not be widely representative of the profession.

Conversely a recent postal survey of London GPs reported that whilst 254/356 (72%) agreed or strongly agreed that palliative care should not be handed over to DNs (interpreted as preference for the continued role of the GP), 27% wanted to hand over palliative care to specialist teams. Those who felt that palliative care was not central to general practice were more likely to come from single handed practices, have had no palliative care professional education, and not to be currently involved in delivering palliative care. Although the response rate in this study was 57% (considered reasonable by the authors for a GP questionnaire), GPs from single handed practices were under-represented in comparison to London primary care as a whole (Burt et al. 2006). As the authors suggest, since GPs with more interest in palliative care might have been more likely to respond, it may be that a higher proportion of GPs than reported would prefer to hand over care to specialists. In addition since GPs are contractually obliged to provide palliative care, this may prevent them from expressing an opinion which might indicate that they are failing in their contractual duties.

Thus, it would seem that at least a substantial proportion of GPs consider palliative care as central, with a group who would prefer to transfer care to specialists. This is supported by a study illustrating the extent to which GPs vary in their use of specialist palliative care services. Shipman et al. (2002) interviewed 63 GPs in inner city, suburban and rural areas in England and reported that whilst the majority of GPs use specialist services as a resource and others rarely used them, seven completely handed over responsibility of palliative care patients to specialist teams.

Whilst the new contract gave GPs a contractual obligation to provide terminal care, they can opt out of their out of hours obligation. How this will affect the delivery of palliative care in out of hours periods (i.e. the majority of the week) is unknown. Since 1995, GPs had been working more frequently in co-operatives which had raised issues relating to continuity of care, particularly as it seemed co-operatives rarely had clinical information available regarding terminally ill patients (Barclay et al. 1997a; Munday et al. 1999; Munday et al. 2002; Burt et al. 2004). However, even

before this time, since GPs worked in extended rotas, and up to 40% had used deputising services (Hallam, 1994), patients were unlikely to be visited by their own GP out of hours. Whilst some GPs will give their dying patients their personal number (Shipman et al. 2000), this is often just during the last few days (unpublished data Aberdeen co-operative survey 1998).

Evidence regarding the effectiveness of GPs' delivery of palliative care has been reviewed systematically by Mitchell (2002), who noted that although GPs had a central role internationally, there are wide variations in terms of their skills and training in palliative care. I will review only evidence related to UK practice.

2.7.1.1 Post-bereavement studies assessing effectiveness of palliative care

In common with evaluation of palliative care services generally (Robbins, 1997), rating the effectiveness of community palliative care is challenging. Involving the patient in research is problematic for ethical (Jubb, 2002) and practical reasons (Addington-Hall, 2002) and no clear and unproblematic outcome measures exist (Hearn and Higginson, 1997).

Many studies have recruited bereaved carers as proxies for the patient following Cartwright et al.'s (1973) seminal 1969 study. The regional study of care for the dying (RSCD), which surveyed 3696 deaths from 20 health districts representative of the UK (Addington-Hall and McCarthy, 1995a) has provided very useful evidence which will be drawn on in this review as will studies using a postal questionnaire 'VOICES' for bereaved carers (Addington-Hall et al. 1998c).

Although post bereavement studies are a useful method, they are not without problems and these have been highlighted by several authors. In comparing contemporaneous reporting between patients and relatives, the *presence* of physical symptoms is more concordant than reporting of the *severity* of symptoms or the distress caused by them (Field et al. 1995). Hinton (1996a) found that in post bereavement interviews pain was reported as having been more severe, whereas Higginson et al. (1994) reported pain severity as being polarised (more mild or more severe) in comparison with contemporaneous interviews. Hinton suggests a possible explanation of this effect is that episodes of particularly severe symptoms may leave a lasting impression on the relative and are therefore reported as being more severe.

Psychological symptoms have been shown to produce less concordance between contemporaneous and post bereavement interviews than physical symptoms and there seems to be a large amount of disagreement between patients and relatives on the particular symptoms which had led to admission (Field et al. 1995).

Seale (1998b) analysing transcriptions of interviews with bereaved relatives found that the bereaved relatives use the interview 'to defend their moral reputations and to understand distressing deaths' p1518. Thus their accounts carry a particular perspective which needs to be taken into account in interpreting carer satisfaction surveys.

2.7.1.2 Evidence of effectiveness of GP care

On the whole relatives have been satisfied with the care received from GPs with three studies reporting excellent or good care by 69%, 72% and 73% respectively (Hanratty, 2000; Addington-Hall and McCarthy, 1995b; Lecouturier et al. 1999). Satisfaction with GP care seems to be particularly related to accessibility and diligence, with higher levels of satisfaction expressed for GPs who visited frequently (Fakhoury et al. 1996) and willingness to make home visits, time taken to listen and discuss issues and making an effort to control symptoms (Lecouturier et al. 1999). These reports from large retrospective surveys of carers views, have been supported by Grande et al. (2004), who in a qualitative study, as well as confirming issues regarding accessibility, highlighted that carers were particularly satisfied with GPs who went 'beyond their remit to make themselves available' p775, such as giving their personal number, visiting when not on duty and attending without being summoned. In addition, this study highlights the importance carers attach to GPs offering support for themselves, including information about the patient's illness and symptom control, an aspect also noted by Fakhoury et al. (1996). Accessibility and attention to detail by GPs were aspects also seen as important by terminally ill patients in a recent Dutch study (Borgsteede et al. 2006b).

Effectiveness of symptom control by GPs as reported by carers in post bereavement studies is more problematic. Reports continue to suggest that pain is not always well controlled despite GPs being familiar with the modern approach to pain management (Barclay et al. 2002). Dewi Rees (1987) reported a change in GP analgesic prescribing with more appropriate regimes being used in 1986 in comparison with

1981, in addition to syringe drivers becoming readily available. However, whilst Jones et al. (1993) reported that 138/146 (94.5%) of patients dying at home had very good or moderate pain control, other studies report lower levels, 44% (Addington-Hall et al. 1991), 53% (Hanratty, 2000) and 53% (Addington-Hall and McCarthy, 1995b). Bias may have been introduced in Jones et al. (1993) since the sampling method involved GPs nominating relatives of recently deceased patients, whereas the other three studies used death certification to generate their samples. In addition, Addington-Hall and McCarthy (1995b) report on a much larger sample of 2074 carers in comparison to Jones et al with a sample of 207.

The ability of GPs to recognise symptoms is an important precursor to achieving symptom control and this is an area which has received attention. Millar et al. (1998) report on a study in which GPs were asked to assess symptom control in 643 patients four weeks after death, with half of these patients also reported on by the DN involved. Whilst there was a high level of agreement between GPs and DNs for aspects of symptom control, levels of poorly controlled symptoms were substantially lower than reported in post bereavement studies with relatives.

GPs have also been found to report symptoms less than patients. When GPs reporting of symptoms for patients was compared to that revealed by patients in interviews with them, GPs were found to under report all symptoms apart from loss of appetite which they over reported. Under reporting was greater in symptoms which GPs reported as more difficult to control, suggesting that GPs may be less likely to ask patients about symptoms which they are less confident in controlling (Grande et al. 1997a). The authors of this study, reflect on how Cartwright et al. (1973) had reported that patients were less likely to consult about symptoms which they saw as inevitable and untreatable. Good communication and attention to detail are suggested as vital elements of effective symptom control (Twycross and Wilcock, 2001), i.e. the issues highly valued by carers and patients. Interestingly, spending time with patients and effective symptom control are two areas in which specialist palliative care services score consistently more highly than primary care in retrospective studies (Lecouturier et al. 1999; Hanratty, 2000). This it has been suggested is the main influence in enabling specialist palliative care teams to deliver effective

palliative care (Fordham and Dowrick, 1999), a luxury the authors suggest is not open to busy primary care teams.

However, there is evidence that time might not be the only relevant factor, since GPs might not possess all of the knowledge and skills necessary for effective symptom control. Whilst the majority of GPs demonstrate a good grasp of the basics of palliative pain control, fewer demonstrate this in more complex areas (Barclay et al. 2002). In addition a substantial number of GPs do express a lack of confidence in areas of symptom control (Grande et al. 1997a) and wish for more education in palliative care particularly in symptom control for non-cancer patients (Shipman et al. 2003).

2.7.1.3 Training in palliative care for GPs

Whilst undergraduate teaching in palliative care was recommended by the Wilkes report (Working Group on Terminal Care, 1980), it has remained an area to which little time has been devoted in the curriculum with many newly qualified doctors feeling unprepared to care for dying patients in the late 1990s (Charlton and Smith, 2000). Two surveys conducted by Barclay et al, one in East Anglia and the other in Wales (Barclay et al. 1997b; Barclay et al. 2003), reported similar results; that GPs had received very little training in palliative care in medical school or as junior hospital doctors, receiving more as GP registrars (GPR) and as GP principals. The majority of GPR training schemes do offer some training in palliative care, although the amount of time dedicated to it is often relatively short and lack of resources can mean difficulty in finding experienced clinicians to teach or finding adequate hospice placements for trainees to gain experience (Lloyd-Williams and Carter, 2003). Evidence from the West Midlands, suggests palliative care training can be effective with GPR confidence increasing during the practice attachment year (Charlton et al. 2000).

2.7.1.4 Conclusion

GPs are central to the provision of palliative care in the community although there seems to be a wide range of opinion towards their place in this, not least amongst GPs themselves. Most GPs see palliative care as an important aspect of their work which can be highly rewarding, whilst a minority prefer to hand over care to others.

Satisfaction of bereaved relatives seems linked to the GP providing high levels of continuity and a personal service. Some deficiencies exist in GPs' knowledge base, particularly in areas of complex symptom control, which may be related to lack of time given to training both at the undergraduate and postgraduate level. Recent contractual changes leading to most GPs opting out of being responsible for providing 24 hour care may change GPs roles further (Heath, 2007), but it is too early to be sure how this might materialise.

A number of studies have illustrated the importance GPs attach to DN services (Field, 1998; Wilkes, 1984; Burt et al. 2005; Cartwright, 1991a) and also to palliative care CNS services (Barclay et al. 1999), although opinions about the latter seem to be more varied (Burt et al. 2005; Cartwright, 1991b). I will now consider the issues surrounding the provision of these community nursing services for palliative care.

2.7.2 Community nursing

This section considers the literature concerning DNs and palliative care CNSs from 1988 onwards. From this point on more systematic research has been undertaken regarding the roles and effectiveness of both groups of nurses. Whilst the work of community nurses in caring for the terminally ill had been recognised as central, over the previous 40 years it was mostly seen as secondary to that of doctors. However, in this period their role as independent practitioners in their own right has been more apparent.

2.7.2.1 District nurses

In numerous studies since 1990 DNs have described palliative and terminal care as being a central part of their work (Hatcliffe et al. 1996; Goodman et al. 1998; McHugh et al. 2003; Mcilfactrick and Curran, 2001), considering their role to be one of a co-ordinator of care (Dunne et al. 2005; Bliss, 2000; Mcilfactrick and Curran, 2000). Patients and carers have identified that they are the professionals who have the greatest regular contact with palliative care patients in the community (Beaver et al. 2000). Their central role in palliative care continues to be officially recognised in national strategy (NICE, 2004) particularly with regard to enabling patients to remain at home (DH, 2000a).

Grande et al's study (1997a) suggested that DNs have complementary skills to GPs with more confidence in dealing with incontinence and bed sores. In addition GPs were more likely to overlook these problems compared to those which they expressed confidence in managing, e.g. pain and nausea; suggesting that early referral to DNs could be clinically beneficial. In addition many studies highlight DNs' preference for early referral (Luker et al. 2000; Goodman et al. 1998; Seale, 1992; McHugh et al. 2003) even from the point of cancer diagnosis (Hatcliffe et al. 1996), particularly to enable close and supportive relationships to be developed with patients and carers (Luker et al. 2000). In post bereavement studies, levels of carer satisfaction with DNs work has been high (73 – 87%) and consistently higher than for GPs (Addington-Hall and McCarthy, 1995b; Lecouturier et al. 1999; Addington-Hall et al. 1991) with dissatisfaction being related to the DN being rushed, the service being poorly co-ordinated (Lecouturier et al. 1999; Addington-Hall et al. 1991) or to a feeling that the DN was not knowledgeable (Lecouturier et al. 1999).

Little had been reported of the training received by DNs until the 1990s. Seale, (1992) reported that 55% of DNs in the 1987 national study had received some training in terminal care, although the nature of this was not described. In 1996 Hatcliffe et al. reported that in a questionnaire survey of 148 DNs in South London 84% had received training, with 11% having undertaken English National Training Board courses in palliative care and 2% having diplomas or degrees. DN self expressed learning needs have been varied and include symptom control (Seale, 1992; Hatcliffe et al. 1996; Mcilfactrick and Curran, 2000), bereavement care (Hatcliffe et al. 1996), training in breaking bad news, dealing with difficult situations, non cancer symptom control (Addington-Hall et al. 2006) and non-pharmacological pain control (Addington-Hall et al. 2006; Mcilfactrick and Curran, 2000). Training of DNs in palliative care was a key policy of the NHS Cancer Plan (DH, 2000b) in which £6 million was invested in a training programme delivered by the 34 English cancer networks. This was the largest and most focused programme of its kind in palliative care and the recently published evaluation reported that following training, the confidence of DNs particularly those with little previous training in palliative care or no formal DN qualification, was increased. However, there was no change in either carer satisfaction or GP assessment of DN knowledge or skills (Addington-Hall et al. 2006).

Patients with end stage cardiopulmonary disease have been reported as being less likely to receive input from a district nurse (Exley et al. 2005; Edmond et al. 2001; Burt et al. 2005). Conversely Gore et al. (2000) who compared 50 COPD patients with 50 lung cancer patients found that more patients with COPD received DN support. This possibly arose as a result of their sampling strategy since the cancer group were recruited early in their diagnosis when they were still active, whilst the patients with COPD (i.e. chronic disease) might already have had greater nursing needs. Goodman et al. (1998) proposed that the special role DNs identified for themselves in caring for terminally ill cancer patients possibly has the detrimental effect of lessening the importance they place on nursing those with chronic non-malignant illnesses. In addition, patients with non-malignant disease are less likely to receive care from specialist nurses (Barclay, 2001), making the DN role all the more vital (Bliss, 2000).

Care of patients with chronic illness may be changing since the introduction of 'NHS case managers' or 'community matrons' whose role is to coordinate care for these patients, particularly the ones at increased risk of emergency admission to hospital (Murphy, 2004). Whilst this development is modelled on services successfully employed in the USA (Wagner, 2000), plans for each PCT to reduce emergency admissions by 10 – 20% by developing 3000 such posts by 2008 are ambitious (Murphy, 2004). Whilst early results from 62 pilot practices in the UK suggest that admission rates have not been reduced (Gravelle et al. 2007), equally worrying is the possible effect this may have on the district nursing service with many senior and experienced DNs likely to move into these posts (Morrison, 2005).

Major changes in the DN workforce, moves to prevent home visits for all but the totally house-bound (Parkinson, 2006) and possible privatization of DN services (Meehan, 2006), makes predictions about DN future role difficult. More research will be needed to monitor the effect of these developments and to ensure that patients receive the care which DNs have traditionally delivered.

2.7.2.2 Palliative care clinical nurse specialists (CNS)

Whilst the aims of providing support for cancer patients and their families have not fundamentally altered since the introduction of Macmillan nurses in 1975, changes in the role of nurses, particularly the evolution of the clinical nurse specialist (CNS), led

to the evolution of the Macmillan nurse from a terminal care nurse into a palliative care CNS (Webber, 1994). Other changes which have affected the role of Macmillan nurses include changes in strategy towards dying patients and palliative care. In 1987 the first official NHS strategy was adopted (Clark and Seymour, 1999) (Box 2-1 page 70) which identified that care of the dying was primarily the role of the primary care team, with the Macmillan nurse being seen as a specialist resource and not a primary carer (Webber, 1994). Evidence suggests that even before this time referrals to Macmillan nurses were changing, becoming more medical in nature with an increased role for them in symptom control (Nash, 1992). The 1990 'Regional study of the care of the dying' (RSCD) seems to support this, reporting that patients with multiple symptoms were more likely to be referred to Macmillan nurses than those with fewer symptoms (Addington-Hall and Altmann, 2000), suggesting that by this time Macmillan nurses were more likely to see patients with complex physical problems.

The palliative care CNS role has been identified as including: teaching generalist staff and student nurses, taking on a leadership role, giving specialist advice (indirect patient care) and participating in research (Webber, 1994) and later, strategy development (Hill, 2001) in addition to direct patient care. Whilst this extended role affected the time available for direct care, Skilbeck and Seymour (2002) identified, in the largest study to date of Macmillan nurses (Skilbeck et al. 2002), that over 50% of their time was still spent in direct patient contact. However, service development has introduced the need for a new set of skills, leading Clark et al. (2002) to comment:

'Part of the skill of the Macmillan nurse is to pursue two linked but separate objectives. The first is to achieve the best outcome in any given episode of care for an individual patient; the second is to raise care standards, generally, in hospital or community. The competing demands of 'clinical expert' and 'change agent' make up the daily pattern of work and help to explain its diversity and the need to employ both formal and informal modes of organization' p380.

The extended role of the Macmillan nurse combined with a marked heterogeneity in the constitution, organisation and working practices of individual teams (Clark et al. 2002) is possibly at the root of continued confusion as to the responsibilities of

Macmillan nurses, even in the minds of DNs with whom they generally work closely (Aitken, 2006).

A further area of possible confusion concerns their direct patient work. The Macmillan nurse role became more 'medical' in nature, along with general developments in CNS work, with nurses' work extending increasingly into traditional medical areas (Shewan and Read, 1999). However despite a 'medicalization' of their role, around 60% of their work has been identified as being 'support' (Nash, 1993) or 'emotional care' (Skilbeck et al. 2002). Skilbeck and Payne (2003) identified this care as including: firstly developing a relationship with the patient and carer then using reassurance, empathy, encouragement, sympathy, touch and physical proximity as support. Quantifying this work clearly is problematic as it is inherently complex and varies according to the immediate situation. These skills arguably lie on the boundary between technical expertise (e.g. counselling) and 'emotional labour,' an aspect of 'traditional' nursing work (Smith, 1992). I will discuss emotional labour in some depth in Chapter-6 (Section 6.3 page 241) when I present findings from the health care assistant project.

General levels of satisfaction with palliative care CNSs seems to be particularly high amongst informal carers (Lecouturier et al. 1999; Jarrett et al. 1999; Rhodes and Shaw, 1999) and generally high amongst health care professionals (Seale and Cartwright, 1994), although this is more mixed (Boyd, 1995; Cox et al. 1993). In Seale and Cartwright's 1987 study, DNs and hospital consultants were particularly enthusiastic about Macmillan nursing services, with 97% of DNs finding them helpful or very helpful and 81% of consultants highlighting the development of community Macmillan services as being helpful or very helpful. GPs were not so convinced of the need to increase community Macmillan services with only 47% of those who had not experienced such a service agreeing, rising to 67% if they had experienced it (Seale and Cartwright 1994). However, lack of clarity over professional boundaries between Macmillan nurses and DNs (Clark et al. 2002), a threat of deskilling (Cox et al. 1993) and resentment at the perception being the 'handmaiden' of the Macmillan nurse (Shipman et al. 2006) might lead to ambivalence by at least some DNs. This seemed most marked in a study of commissioning priorities for palliative care in the Cambridge area. DNs rated

Macmillan nurses as having the lowest priority out of 11 possible services in comparison to GPs who rated them fourth (Barclay et al. 1999). Local variation in services, attitudes and priorities are likely to affect such views substantially.

Concerns amongst both GPs and DNs at the lack of out of hours availability of Macmillan nurses is a common and recurring theme (Seale and Cartwright, 1994; Higginson, 1999; Boyd, 1995; Burt et al. 2005; Corner et al. 2003). Twenty four hour availability of specialist palliative care has in fact been a NHS policy for over 10 years (DH, 1996) and has been endorsed as a basic standard for palliative care (NICE, 2004), however this is still very variable nationally (Munday et al. 2002).

Whilst Macmillan nurses are appreciated by patients, carers and professionals, questions regarding their effectiveness are more difficult to address. As with many services within palliative care, the aim is to offer holistic high quality care, in conjunction with other generalist services. The complexity of palliative care and the difficulty of isolating the component delivered by Macmillan nurses, the lack of suitable end points and the practical and ethical issues inherent in testing such a service experimentally are all pertinent issues (Corner and Clark, 2003; Grande and Todd, 2000). A further exploration of these issues will be made in the Chapter-4.

Corner et al. (2003) however did evaluate effectiveness by following a cohort of 76 patients over 28 days who had been referred to Macmillan nurses. Using quality of life scores and the 'Palliative Outcome Score' (POS) statistically significant improvements in emotional wellbeing, cognitive function and anxiety levels were demonstrated in the first 7 days, but this effect was not maintained at day 28, arguably due to the deteriorating condition of the patient. Qualitative measures of improvement did suggest several areas of benefit including: a supportive approach to care, taking time listening to patients, providing information and acting as an intermediary with other professionals, managing complex cases by taking a co-ordinating role in addressing symptoms, providing support for families and carers and providing information and emotional support. Negative effects included patient and carer concerns about too many health care personnel being involved and Macmillan nurses being seen by some patients as a metaphor for 'imminent death.'

2.7.2.3 Conclusion – community nurses

Macmillan nurses and DNs have worked closely over the last 30 years and continue to do so. Several studies since 1990 have indicated that their work is highly valued by service users and professionals. Many Macmillan nurses have previously worked as DNs. As the role of both groups has evolved over time, there is evidence of conflict due to lack of clarity in roles (particularly for Macmillan nurses) and a sense of the divisions between specialist and generalist nurses. Some of these issues are perhaps heightened by the division between technical-rational clinical interventions and holistic health care which is particularly pertinent to the field of palliative care (Corner, 2004). These tensions have implications for multidisciplinary working within the wider team, particularly in the ‘supportive triangle’ of DN-Macmillan nurse-GP (Burt et al. 2005). Aspects of multidisciplinary working will be explored in the following section.

2.8 Multidisciplinary working

The WHO definition of palliative care highlights multidisciplinary working as a fundamental principle for effective palliative care (WHO, 2002) which as Clark and Seymour (1999) point out should denote a lowering of disciplinary boundaries; however they conclude the extent to which this occurs in practice is unclear.

Whilst the evidence for the effectiveness of multidisciplinary working has been described as unclear (Opie, 1997; Zwarenstein and Reeves, 2000), its importance in palliative care has not been in doubt. GPs and DNs have been identified as having distinct and complementary roles both necessary for holistic care (Grande et al. 1997a; Robbins, 1997). Effective multidisciplinary working in palliative care has been identified as vital in enabling patients to die at home (Thorpe, 1993); as a prerequisite for delivering high quality palliative care by GPs and DNs (King et al. 2005); encouraging development of effective guidelines and protocols through a sense of shared ownership (Robinson and Stacy, 1994) and providing a forum for education (Jones, 1995).

Corner (2003) has suggested that the multidisciplinary team in specialist palliative care ‘may be somewhat fictional of what we desire palliative care to be, rather than the reality of palliative care service provision’ p10, going on to suggest that interagency care, with professionals working in parallel, rather than exhibiting true

multidisciplinary team working may be more characteristic of the discipline. Corner uses Rosenfield's taxonomy (1992) to distinguish between three types of team working: multidisciplinary, interdisciplinary and transdisciplinary which can be summarised as in Box 2-2.

- Multidisciplinary: members work in parallel or sequentially from a disciplinary specific base to address a common problem.
- Interdisciplinary: members work jointly, but still from a disciplinary specific basis to address a common problem.
- Transdisciplinary: members work jointly using a shared conceptual framework drawing together disciplinary specific theories, concepts and approaches to address a common problem.

Box 2-2 - Rosenfield's taxonomy adapted for a health care team

By this scheme Corner's interagency care looks very much like Rosenfield's multidisciplinary working. For Corner (2003) it is important that palliative care teams should strive towards a transdisciplinary model of working. Whilst this seems to be an attractive proposition, it is unclear what the precise nature of the 'shared conceptual framework' for palliative care should be. Corner does suggest that the patient should become more central to the team where they can direct their own care, although how this can be put into practice is something she does not tackle. Whilst these could be seen as aspirational issues which need further exploration, it seems that much is still needed to achieve consistent working at the multidisciplinary or interdisciplinary level.

Patients and carers express satisfaction when palliative care is well co-ordinated (Grande et al. 2004; Lecouturier et al. 1999) and dissatisfaction when it is not (Worth et al. 2006). Coordinated care and continuity were discussed in Section 1.4 (page 27) and will not be discussed further at this point although it is important to note that achieving these aims will require professionals working at a deeper level than merely performing parallel tasks in a co-ordinated way (Corner, 2003).

Opie (1997) suggests that in order for a health care team to achieve an interdisciplinary or transdisciplinary approach several factors are needed including:

- Common goals

- Institutional support
- Sufficient expertise to develop practice
- Encouragement of multiple partners to participate
- Attention to team building
- High commitment to the team
- Sufficient financial resource p263.

Bliss et al. (2000) reviewing palliative care literature identified several factors which have mitigated *against* effective team work including: lack of clarity in the aims of a service, lack of understanding of other disciplinary roles within the team and members working within different employing organisations. In addition Opie (1997) suggests that in ‘settings with strong hierarchical traditions, no tradition of multi-professional work and absence of a legitimating ideology’ p264, establishing an effective multidisciplinary team approach may be difficult.

These factors illustrate why there may be inherent difficulties in operationalising multidisciplinary teamwork between the GP, DN and Macmillan nurses. Unlike a hospice team, these professionals rarely form a ‘natural’ team in that they frequently do not work from the same premises, they have different organisational arrangements, and they are members of other teams. In addition for each patient the composition of the team may be different – DNs may cover more than one practice and work with several GPs, and Macmillan nurses will probably work with several different primary care teams. DNs and Macmillan nurses will also have to adjust to different working patterns and attitudes of GPs which may vary significantly as several studies have highlighted. Many GPs see palliative care as central to their work, however a substantial minority would prefer to hand over care of terminally ill patients to specialists (Shipman et al. 2002; Burt et al. 2005), other GPs use specialist services only very rarely (Shipman et al. 2003; Robbins et al. 1996) and those who do refer may vary significantly in referring practises (Shipman et al. 2002; Pugh, 1996). Some GPs whilst espousing the concept of multidisciplinary working might have difficulty in working effectively in this way. Speed and Luker (2006) exploring DN and GP relationships have recently suggested that:

‘The shift in power [through health service policy] to general practitioners (GPs) has meant that they can exercise ever-increasing authority over nurses in their employ’ p883.

Data from our own case study of GSF practices (submitted for publication) illustrates how some GPs may not be aware of the power differentials at work leading to the marginalisation of DNs; some holding the opinion that their working relationship with the DN is excellent, with the DN being more circumspect. Since the GP’s surgery will usually form the natural site for multidisciplinary meetings this might have the potential of reinforcing the GP’s dominant position within the team and thus making true multidisciplinary working problematic.¹⁵ I will examine power relationships in community palliative care when I discuss the results of the emergency admission study in Chapter-5 (Section 5.5.4.1 page 224).

In palliative care Carpenter (1993) suggests that the central role of district nurses arises as the result of ‘curative medicine’ relinquishing control of patients who are no longer curable to nurses, whose function is to care. Whilst this may be a factor, evidence suggests that the issues may be much more complex as a result of shifts within traditional medical-nursing relationships. GPs themselves may feel marginalised by specialists in care of patients with advanced cancer so that they have become unclear of their role (Jeffrey, 2000; Exley et al. 2005). Conversely Macmillan nurses are cast in the role of specialist, with DNs expressing concern that they are seen as the handmaidens of Macmillan nurses when caring for the terminally ill (Shipman et al. 2006). The generalist role in nursing is also undervalued even by some patients, who identify the specialist role of Macmillan nurses more highly than that of DNs (Barclay et al. 1999). Thus, rather than simply ‘cure over care’ the supposed supremacy of specialists over the generalist may be an equally important factor.

In order for high quality palliative care in the community to be achieved and to allow the patient choice over place of care, strengthening of team working is paramount. Whilst it is desirable for palliative care teams to move from multidisciplinary

¹⁵ In an extreme example: as a specialist registrar I was invited to a practice palliative care meeting. Lunch was provided and I was invited to join them by the GPs. However, I had been forewarned by the Macmillan nurse that at this meeting doctors eat, nurses don’t and decided on a policy of quiet solidarity with the nurses. I have been to many practices where if lunch is provided everyone eats!

towards interdisciplinary and transdisciplinary care, this may have major problems for many because of fundamental organisational issues. However, professional dominance and prejudice may be reduced through openness, reflexivity and mutual respect (Opie, 1997), whilst power differentials need to be acknowledged and addressed (Pearson and Jones, 1994; Corner, 2003). However, the danger is that through this process some teams may become exclusive, concentrating on their own maintenance at the expense of patient care (McWhinney, 1998; Stiefel, 2003).

The whole team taking a reflexive approach should not only help to protect against dysfunction through dominance and mistrust on the one hand and narcissism on the other, but will also facilitate problem solving particularly for complex cases (Opie, 1997). Hermsen and ten Have (2005) have suggested a 'moral reasoning model' which facilitates decision making through focusing on patient and carer values. This process they proposed also has indirect benefits for the team:

'Through critically analyzing and keeping a distance from one's own point of view and through focusing on the shared process of decision-making, a shared team approach will be developed. As a consequence, it is possible that this higher level of integration of work will neutralize the complicated power relations and hierarchical structures among team members' p566 (ibid).

Organisational stability, adequate resources and a commitment to development through a shared understanding are all vital to achieve these aims in team working (Bliss et al. 2000; Opie, 1997; Cowley et al. 2002). Programmes such as the GSF might go some way to facilitating effective palliative care team working in primary care (Thomas, 2003; King et al. 2005), however, lack of resources (Burt et al. 2005), changes in GP working resulting from the new contract (Walton, 2005; Heath, 2004) and radical changes in community health services (Meehan, 2006) could make this difficult to achieve.

Well co-ordinated team working is essential to effectively manage palliative patients who have complex needs in the community. Breakdown in such care is a potential cause of hospital admission. Surprisingly however, no systematic reviews of the evidence surrounding the reasons for hospital admission in palliative care patients have been published. Since this issue forms a central part of this thesis I will present a systematic review of this literature the next chapter.

2.9 Conclusion

Care of the dying in the community has developed greatly over the last 60 years. Traditionally this has been the role of the GP and DN, but increasingly the care they offer has been supplemented by specialists, particularly the palliative care CNS. The literature confirms that substantial variation exists in how care is delivered to the individual patient, with different local configurations and different approaches by individual practitioners and teams.

Taking a historical approach to the development of community palliative care has enabled some of the complexities of its evolution to be explored. Factors contingent in this process have operated from the personal and local to the systemic and national/global level and have included: development of health technologies;¹⁶ the rise of professional disciplines and development of professional positions and attitudes; multiple local developments (e.g. hospice establishment); research and the dissemination of research findings; the work of pressure groups and charities; government health related policy; social trends; and the charismatic inspiration of leaders, developers and opinion formers within the all of these areas. These factors all interact to make development emergent and unpredictable as discussed in Section 1.5 (page 29).

In Chapter-4 I will suggest a methodological framework for exploring the interplay of all of these factors when I describe Layder's theory of social domains, which I will then use in the analysis of the studies in Chapter-5 and 6. In Chapter-7 I will reconsider the three periods of development of primary and palliative care as an illustration of varying timescales inherent in social emergence.

¹⁶I am using health technology in its broadest term, e.g. the consultation in general practice, advances in the practice of symptom control as well as health delivery devices such as syringe drivers.

Chapter 3 – Systematic literature review: emergency hospital admission for palliative care patients

3.1 Introduction

In this chapter I will present a systematic review of the reasons for hospital admission of palliative care patients. To provide a context for this review, I will give a brief historical overview of patterns of hospital admission for these patients since 1960.

3.2 Historical overview of hospital admission for palliative care patients

In 1960 40% of deaths occurred in NHS hospitals when, as I explored in the last chapter, conditions for the dying in the community were judged as poor (Glyn Hughes, 1960). At that time it was not regarded as the responsibility of the hospital authority to admit dying patients into hospital beds and poor relationships existed between GPs and hospital consultants. Emergency admission would commonly follow a domiciliary visit by a consultant, and GPs would use this process to secure admission; a practice which did not meet with the approval of all consultants (Collings, 1950). Wilkes (1965) reported that GPs had problems admitting 13% of their terminally ill cancer patients to hospital and also reported that dying patients were discharged by hospitals because beds were needed.

Cartwright et al. (1973) in their 1969 national study also reported that whilst 71% of GPs stated that it was easy (rather than difficult or very difficult) to admit young patients with terminal illness to hospital, only 28% responded similarly when asked about the ease with which terminally ill older patients could be admitted. By 1987 when Seale and Cartwright (1994) repeated Cartwright et al's study, admitting the terminally ill older patient had become less problematic with 73% of GPs reporting this as easy, whilst for young patients easy admission had risen to 81%.

During this 18 year period the pattern of admissions also changed. Comparing the results of both studies it was found that patients spending no time in hospital in their last year of life halved from 30% to 16%, whilst the average number of admissions increased by 50%. Deaths in hospital also increased from 56% to 64% between 1969 and 1987, but the average length of stay reduced. Overall it was estimated that in 1987 around 20% of hospital bed days were occupied by patients in their last year of life. Many changes occurred between the late 1960s and 1987, with more therapies

becoming available (Raven, 1990) which will have resulted in more frequent hospital admission for investigation and management.

To understand the reasons for the increase in hospital admissions in the last year of life it is also necessary to consider the wider context. Generally emergency hospital admissions increased by 45% between 1981-1994 (Capewell, 1996), identified as being partly the effect of an aging population (Bernard and Smith, 1998); lowering of the threshold for admission through increased public expectation (Chappell, 1995) and a fear of litigation (Glasby and Littlechild, 2000); a 'revolving door' effect produced by earlier discharge of sicker patients (Capewell, 1996) and an increasing emergency workload for general practitioners (Chambers, 1996). Levels of deprivation and distance from hospital have also been reported as factors influencing emergency admission (Chishty and Packer, 1995).

A key organisational change which arguably facilitated emergency hospital admission was the reform of the NHS in 1974, resulting in community and hospital services becoming the responsibility of a single body – 'area health authorities', rather than local authorities and regional hospital boards (Rivett, 1997). Not only did this go some way to unify hospital and community services, but GPs and hospital consultants were brought together in management and planning within the health service 'in the hope that this would lead to closer understanding and cooperation between them' p2 (Cartwright and Anderson, 1981). Ward (1974) writing that year certainly hoped that these reforms would enable improved co-ordination in terminal care to develop. Therefore, whilst in the past GPs reported difficulty in obtaining beds for terminally ill patients, it is unlikely that currently any GP referring a patient for emergency admission will be refused (Chadwick, 1995).

Unlike the increasing proportion of patients dying in hospital, deaths at home had fallen from 42% to 24% between 1969 and 1987, with more deaths also occurring in other institutions, such as nursing homes and hospices. Aware of these changing demographics, in the 1990s research interest turned to investigating how patient preferences related to actual place of death. Townsend et al. (1990) in a prospective longitudinal interview study with 84 cancer patients judged to be in their last year of life found that 58% of the 84% who expressed a preference wanted to die at home, whilst overall only 29% achieved this. Similar findings were reported by Karlsen and

Addington-Hall (1998) who used a bereavement questionnaire given to relatives of 229 patients who had died; of the 38% of patients reported to have expressed a wish 73% wanted to die at home. These and other studies conducted in a variety of settings worldwide have shown comparable results (Higginson and Sen-Gupta, 2000). In addition, an expressed wish to die at home is associated with an increased likelihood that this will occur. For instance in Karlsen and Addington-Hall's study (1998) whilst the overall home death rate was 21%, of those expressing a wish to die at home 58% achieved this.

As the patient nears death, there tends to be a reduction in the number of patients expressing a wish to die at home (Hinton, 1994a; Townsend et al. 1990), with a seemingly sharper fall in preference for a home death amongst relatives (Hinton, 1994a). However, when asked what they would want in an 'ideal situation', Townsend et al. found that patients' desire for a home death increased towards the time of death. Whilst the evidence that more patients wish to die at home than actually achieve this is strong, Thomas et al. (2004) by surveying patients' preferences over time, using an in depth qualitative interview technique, suggested that patients rarely express their wishes in a categorical way, but tend to lean in one direction or the other, realising the contingency of clinical and social considerations on their choice.

Home death may be less likely to occur in patients who do not have access to good community services (Gomes and Higginson, 2006) and it is evident that services are not uniformly available to all patients in need (Ahmed et al. 2004). In addition, social isolation may mean that certain groups such as the older people are less likely to die at home (Gomes and Higginson, 2006). Regional variation in home death rate may result from other factors. Thorne et al. (1994) noted that in South Devon, in adjacent areas, one served by a community hospital and one with no such facility but with a specialist hospice unit, the home cancer death rate was higher in the area with *no* community hospital (34% vs 29%), whilst the general hospital death rate was also higher (39% vs 17%), however in the area *with* a community hospital 39% died there. Similarly, variations in death rates occur in different contexts with different models of palliative care provision. Hinton found that despite a highly competent and readily available home care team based at St Christopher's hospice, only 29% of patients

receiving the service died at home although this increased to 34% once a day care unit to support home care was established (Hinton, 1996b). In fact home death has been found to be higher if specialist palliative care was provided by services not linked to an inpatient hospice service (Grande et al. 1998).

In all UK studies it seems that for patients, carers, and the general public (Charlton, 1991) home or hospice deaths are preferable, with few people preferring a hospital death (Higginson and Sen-Gupta, 2000). Enabling a home death is a central facet of UK government policy for end of life care (DH, 2003) and is the major concern of initiatives such as the GSF (Thomas, 2003) and Preferred Place of Care Tool (Storey et al. 2003). A lack of hospice beds also means that in the UK many fewer patients can die there than would choose (NCPC, 2006).

These are some of the factors thought to be causally associated with the fact that currently 60% of patients die in hospital. However, the assertion that most terminally ill patients 'are admitted to hospital to die' (Thorpe, 1993; Clark and Seymour, 1999) might be misleading, since it suggests a possible intentional link between admission and death. It is likely that the reasons for hospital admission at the end of life are complex and these are in need of further exploration.

3.3 Systematic review of reasons for hospital admission in palliative care patients

Numerous studies into the determinants of home death have been reviewed (Higginson and Sen-Gupta, 2000; Gomes and Higginson, 2006; Grande et al. 1998), which report on factors associated with the decreased likelihood of home death (often by default = hospital death). On the whole these studies do not report on the issues which have led to individual patients being admitted. Patients may be admitted to hospital on several occasions during their terminal illness (Seale and Cartwright, 1994) and patients admitted to hospital may not die there. Since it is often not possible to predict that death will occur during a particular admission, it is important to understand why palliative care patients are admitted, whether or not this admission ends in death. Insights into reasons for admission could be useful for planning services to enable patients to remain at home. The systematic review presented in this chapter was therefore designed to explore what is reported in the literature about reasons for admission of palliative care patients.

3.4 Aims

To systematically review the UK literature describing the reasons for admission into hospital of patients who have an illness which is advanced and likely to lead to death within one year.

3.5 Method

3.5.1 Scoping exercise

Through familiarity with the literature I was aware of the general lack of studies specifically into the reasons for hospital admission. However I was also aware that relevant empirical data was contained in broader studies into hospital and community palliative care. Also I was aware of, though not so familiar with, a body of literature which explored emergency hospital admission in general, some of it concentrating specifically on admission of older patients (Godden and Pollock, 2001; Hampton and Gray, 1998). This created a potential problem because it was possible that some of these studies contained empirical data relating to patients who had a definable terminal illness, but I considered it impossible to review all literature on emergency hospital admission (an unrestricted search using MESH headings ‘hospital services, emergency’ AND ‘aged’ identified 3999 studies).

Therefore a scoping exercise was undertaken using ‘Google Scholar’ searching on the terms ‘palliative OR terminal OR die OR death AND "emergency admission"' which yielded 994 ‘hits’. This was performed to obtain a broad overview of studies in which these terms appeared and to allow ease of access to identified papers which were all available online. Papers obtained included reports and other documents which would have been missed in database searches of academic literature. The scoping exercise revealed that whilst indeed many papers and reports did exist into emergency admission for older patients, none of those specifically related to patients with terminal illness. The focus of many studies was around the prevention of admission of older people by the use of ‘intermediate care services’ and studies into patients admitted after falls or with acute illness. Whilst many of these patients will have also had terminal illness in the broad sense – including respiratory, cardiac and neurological diseases - the fact that these subgroups were not specifically identified in these studies precluded their inclusion within any useful operative definition. Eleven

of these studies however were retained for future reference and because of general interest.

3.5.2 Methodological issues: terminology and definitions

Searching for articles which provide empirical data into the reason for admission of palliative care patients illustrated a particular problem in terminology. In Section 1.2 (page 19) I discussed definitions of palliative care, and the problems which arise with attempting to clearly define it. If it is too specific, such as including certain disease groups only, patients are missed for whom palliative care is appropriate. A problem exists with basing the definition on prognosis, or time to death since prognosis is notoriously difficult to make (Glare et al. 2003), with many patients expected to die not dying and conversely others dying unexpectedly. If the definition is too broad, then specificity is lost and searching becomes impractical. This problem is well illustrated by Borgsteede et al. (2006) who reported that in a population of Dutch patients who had died, asking their GP to indicate whether ‘death was expected,’ whether they were ‘having palliative care’ or ‘having non curative treatment’ produced a stepwise reduction in the number of patients identified (62%, 46%, 39%).

Patients admitted to hospital in the UK are not normally classified as ‘palliative care patients’, ‘dying patients’ etc on hospital record systems, which predicates against researchers having ready access to these patients, without some form of special search (I will discuss my own methodology in Chapter-5). Patients admitted might be classified as ‘chest infection’ or ‘chest pain,’ categories which might indeed include palliative care patients. Similarly, patients classified as being admitted with ‘chronic obstructive pulmonary disease’ (COPD) or cancer may be either palliative or non-palliative. For instance, studies of patients with COPD may include palliative care patients, but if the researchers did not distinguish these patients as a subgroup it may not be possible to include such a study in a review of palliative care patients.

The classification of type of admission is problematic also. Definitions of ‘emergency admission’ vary between hospitals and within different studies leading to general problems in interpreting statistics which describe the number and proportion of such admissions (Hobbs, 1995; Morgan et al. 1999). However, since the majority of medical hospital admissions will be classed as emergency (Hobbs, 1995) and most

palliative care admissions will be ‘medical’, it is assumed that most palliative care admissions will be categorised as emergencies.

The term ‘reasons for admission’ also needs special attention. Drawing on my clinical and research experience I am aware that there can be many different perspectives on the term ‘reason’ depending on the frame of reference being used and the person to whom the question is being posed. The reason for admission according to clinical staff may be a symptom (pain, nausea etc), a diagnosis (acute respiratory distress, hypercalcaemia etc) or an intention (e.g. admitted for investigation or for ascitic tap). For a patient or carer it may also be a symptom or condition, but framed in a different and also less precise way (e.g. ‘I could not catch my breath’). However, a social reason may be given (‘my daughter was worried about my breathing’) or it could be because of a clinical decision which seems unclear to the patient or is unquestioned (‘the doctor said I ought to go in’).

Reasons also need to be distinguished from the concept of ‘associated with’. This is particularly important for considering hospital admission for patients who are terminally ill and might die, since studies into associations are common (Gomes and Higginson, 2006). Having a disease which is associated with a hospital death, e.g. a haematological malignancy (Grande et al. 1998) cannot be taken as a reason for admission; it is more accurately an association which results from reasons or causal factors.

What of the relationship between reasons and causal factors? Reasons might be seen as *causes as expressed by the person giving the reason*. Therefore, by this definition, causes will be deeper and broader than reasons. Many things which are unapparent to the observer may be causal factors, but these cannot be given as reasons. Causality is complex particularly for social phenomena hence the purpose of *exploratory* empirical research should be to uncover these causal factors revealing their full complexity (Robson, 2002).¹ By using the term ‘reason’ in this way, social research can be seen as enabling more causes to be seen as reasons.²

¹ Complex causality will be explored in relation to critical realism in Chapter-4.

² The link between causes and reasons present the philosophical conundrum of whether reasons (in this concept taken to mean purposeful actions) can be seen as causal, e.g. ‘actions, reasons and causes’ (Davidson, 1963). Discussion of this is beyond the scope of this thesis, apart from acknowledging the potential problems with using these terms.

The study of emergency admissions for palliative care patients is arguably a good exemplar of the complexity of social research, since there is likely to be a complex of causal factors leading to a specific admission (Hinton, 1994b). However, the relative weight of different causal factors may be difficult to elucidate and some may remain hidden, in addition they are also sensitive to opinion or perspective. For example, factors including exhausted relatives and an increasingly weak patient may form the 'context', with escalation in pain being the immediate cause or 'trigger' for admission, whilst the relative's fear of death might remain hidden. Conversely, increasing pain and weakness may be reported as the context with carer exhaustion the trigger. There may be a lack of consensus as to the 'trigger' for admission, or a failure to consider or even appreciate the complex nature of causality. This can be particularly problematic if a single reason needs to be recorded on the hospital IT system or in a survey. For example, a doctor might record that the reason for admission was the need to diagnose and treat a deep venous thrombosis (DVT), whilst from the patient's point of view it was 'unbearable pain in the leg' or from the carer's perspective it was 'inability to cope at home'. Whilst 'DVT' may be recorded as the reason for admission, the patient and the carer's perspectives are no less 'reasons'. Since medical diagnoses are privileged clinically and within the literature, these tend to be reified and accepted with little questioning, whilst reasons from the patient's perspective are ignored or considered as unimportant (Glasby and Littlechild, 2000).

Understanding such complexity including the full clinical and social context is necessary if a holistic view is to be taken, since the subtle interplay of factors involved in causation may then be appreciated. Such a view is important for effective management both at the patient and strategic level. Whilst quantifying the number of patients admitted and the relative proportions for different broad categories is important, the complexity may only be discovered through qualitative methods.

For this study reasons for admission are taken in the broadest sense, hence the importance of searching for evidence which includes the perspectives of patients, carers and health care professionals and includes both quantitative and qualitative data.

3.5.3 Inclusion criteria

Studies considered for inclusion were of adult patients (18 years and older) known to be palliative (likely to die within one year) and who were admitted as an emergency or unscheduled admission, either from their own home or another community institution, e.g. a care home. The admission could have been for final care, i.e. ending in death or an admission earlier in the course of their illness.

Only empirical research studies were considered for inclusion, i.e. surveys, cohort studies, comparative cohort studies, case-control studies, critical incident studies, questionnaires - both current and retrospective, qualitative interview studies and case note reviews. Studies of patients who had been admitted to hospital were included as were studies of patients who were being cared for at home when they needed to be admitted for further care. Some of these latter patients may have been admitted to hospice beds, e.g. Hinton (1994b), however the assumption was made that if this was the case, admission to hospital would have been necessary if hospice beds had not been available. The assumption was also made that hospital admission was not subject to selection criteria or restricted in some way as hospice admission might be (Hockley, 1997). Studies of admission to GP community hospitals were also included because up to 20% of GPs have access to such beds (Seamark et al. 2001) and two fifths of GPs have indicated that access to such beds would be useful for terminally ill patients (Cartwright, 1991a); thus they form an important part of the UK inpatient service for palliative care patients which could be appropriate for further development (Payne et al. 2004).

Since relatively few studies with the primary aim of investigating reasons for admission have been reported, inclusion criteria were extended to include papers giving any data relating to reasons for admission for palliative care patients. Thus a wide variety of studies could be included, the primary aims of which were for example: exploration of the experiences of palliative care patients or carers and needs assessments for community palliative care.

Whilst studies needed to make reference to the reasons for admission of palliative care patients to merit inclusion, there was no restriction to the type of person providing the information. Since reasons for admission are complex and require many perspectives to be adequately explored, studies in which the participant was the

patient, carer or health care professional were included, as were studies which used documentary evidence, such as case notes or admission records.

3.5.4 Exclusion criteria

Specific exclusions included studies which were single case reports, general descriptions of practice, policy documents or opinions expressed by practitioners or researchers in editorials and review articles. Specific surveys of hospice or specialist palliative care unit admissions were not included since such admissions may be highly selective and variable according to hospice admission criteria, although studies which compared hospice with hospital admission were included, if they otherwise met the inclusion criteria.

Only studies conducted in the UK were included, because health systems in other countries are significantly different. For instance in a Canadian study hospital deaths *decreased* between 1986 and 1998 from 82.4% to 59% (Huang et al. 2002) whilst UK hospital deaths remained relatively static for the same period. It is possible that some European countries have systems which resemble the UK more than North America (e.g. Netherlands, Denmark), however following a brief review of current descriptions of primary care in other countries it was decided that no country had a system which was sufficiently similar to that in the UK to be included (Meads, 2006).

Studies which provided data related to hospital deaths without any information on reasons for admission were excluded as were studies which described planned admissions alone, e.g. for surgery, oncological therapy or investigation. Studies of children were not included.

3.5.5 Search strategy

The search strategy included performing searches on electronic databases including MEDLINE, CINAHL, HPMC, IBSS and PsychoINFO, using online resources. In addition hand searching of contents pages of relevant journals and abstract lists for relevant palliative care congresses was undertaken. A full description of the searches made is contained in Box 3-1.

The abstracts of articles whose titles indicated that they may have fulfilled inclusion criteria were read. For those articles whose abstracts indicated that the paper was likely to fulfil inclusion criteria, the complete paper was read. Since the majority of

articles which were included reported studies whose primary aim was not to investigate reasons for admission, any article which reported palliative care patient or carer experience in the community was read so that any data describing reasons for admission could be uncovered.

If an article indicated that other publications reporting aspects of the same study had been published, these were also accessed and considered for inclusion. If further publications were indicated but references were not given, journal specific citation databases and SCOPUS were consulted.

The authors of conference abstracts which fulfilled inclusion criteria or which indicated that a full paper may contain relevant data were contacted and were asked to send copies of posters or presentations and asked to provide references if a journal article had subsequently been published. Finally, MEDLINE searches for the papers of known palliative care health service researchers were made to check for further relevant papers.

3.5.6 Analysis of papers

The papers which were included in the study were read and summarised (Table 3-1). A note was made of the data referring to reasons for admission in each paper and these were compared with data emerging from other papers. This comparison between papers enabled headings to be generated under which the findings were described and discussed.

Since reasons may be framed and categorised in several different ways depending on the context in which they are recorded or discussed, having summarised the reported findings with respect to reasons for admissions (Table 3-1), I have defined four categories which emerged from these summaries as an analytical device (Table 3-2). The first two categories are the reasons relating specifically to the patient and carer which might arise in their narrative or experience. Reasons falling into these categories may have been the trigger for admission in some cases, however, this is also likely to have been influenced by what I have defined as ‘contextual factors’ – the third category. The fourth category is ‘professional construction’, which clinicians might commonly use to define reasons for admission.

1) Medline: (MESH headings) - Patient Admission OR Hospitalization OR (keyword) Hospital admission.mp OR Emergency Admission OR Emergency Hospital Admission AND (MESH headings) Palliative Care or Terminal Care.

This produced 642 papers, of which 35 were selected for review of the complete paper having read the abstract.

2) Cinahl: (MESH) - Emergency Service OR Emergency Care OR Patient Admission OR Hospitalization OR (Key words) Emergency Admission.mp OR Hospital Admission.mp OR Emergency Hospital Admission.mp AND (MESH) Palliative Care OR Terminal Care

This produced 121 papers of which 6 were selected for full inspection.

3) HMIC, IBSS and PsychoINFO – Accessed via OVID webSPIRS 5.1 search facility
Search terms Death OR Dying OR Terminal Care OR Palliative Care AND Hospital Admission or Emergency Admission

205 papers identified of which 3 selected for full inspection.

4) Medline Search for palliative cardio-respiratory disease including searches (MESH headings) COPD OR Heart Failure AND Terminal Care OR Palliative Care.

5) Medline Search for palliative care patients admitted to oncology units (MESH headings) Services, Oncological OR Radiation Oncology OR Medical Oncology AND Hospitalization OR Patient Admission.

6) Searching through MEDLINE listed publications for principle UK based health service researchers in palliative care (I Higginson, J Addington-Hall, C Seale, C Todd, D Clark, J Seymour, S Payne, D Seamark and G Grande) to identify any publications not identified in other ways.

7) Hand searching – Palliative Medicine from 1994, Journal of Palliative Care from 1994, British Journal of General Practice 1994 and International Journal of Palliative Nursing from 1996 (the first issue) as these are the journals which principally contain publications relating to UK community palliative care health services research.

Box 3-1 - Systematic searchers: Identification of studies for the literature review

Table 3-1 - Summary of papers identified for the literature review

No	Name of Study	Summary of features	Research Method	Main stated aim of study	Site of study	Sample	Main findings related to admission – isolated from other findings which give context and will be discussed in the text
1	Herd 1990	R Q (rel/HCP) C Hme Sec PC	Structured interviews: carer, GP and DN	Describe terminal care in rural area	West Cumbria	157 consecutive dying patients terminal period of at least 1 week	Reason for hosp admission leading to death = Lay carer unable to continue to give care 45%, No lay carer 22%, Other social reason 4%, Symptom control 55%, Investigation 24% Nursing needs 20% Treatment 13% Other medical 2%.
2	Townsend et al 1990	P L I C Hm Sec PC	Prospective + bereavement interviews	Preference place of final care	Northwick Park Hospital	84 terminally ill cancer patients identified by specialists	42 died Northwick park hospital: Reasons for admission known for 30: 10 admitted for terminal care, 9 for symptom control, 9 for Ix and 2 for chemo and radiotherapy
3	Hinton 1994b	P L I C Hm Primary PC	Longitudinal cohort study	Which pts admitted from home care	St Christopher Home care	77 cancer patients	55 died IP 22 home. Symptom [^] , rel fatigue [^] , Reduction in QoL, less acceptance of disease, less stoical relatives, longer time in home care A/W admission. Conclusion: complex factors involved
4	Tomlinson et al 1995	P Q C/NnC GPH. Prim NonPC	Prospective observational	Baseline for comm. hospital planning	Leicestershire GPH.	685 GPH admissions	71 (10.4%) cancer patients. 41 terminal care, 18 respite care. 77pts died. 22 admitted acute care. No "NnC" identified specifically as palliative.
5	Seamark et al 1995	R Q C H/GPH/Hme /Hspc. Sec PC	Retrospective post bereavement questionnaire	To determine doctors views regarding place of death	Exeter and District	1022 cancer deaths Questionnaires sent to GP and hospital consultant.	Admissions to hospital: GP vs Hosp doc + agreement: Ix 39.7% vs 29.4% + 54.8%, Sympt cont 19.7% vs 24.2% + 50%, active Rx, 15.5% vs 19.9% +57.1%, social reasons 15.1 vs 10.0 + 44.4%, Pain Mx 6.3% vs 9.5% +35.7%, reason unrelated to cancer 3.8% vs 4.7% + 20%. In only 45% GPs had expected death.
6	Seale and Kelly 1997	R C C I C H/Hspc Sec PC	Bereaved spouse I	Compare dying hospice v hospital	St Christopher and local H	33 hospice and 33 hospital deaths	Hospital: 30% urgent GP call. 36% called ambulance Hospice 0% urgent GP call 3% (1 pt) called ambulance.
<p><i>Abbreviations used in table:</i> P=Prospective, R=Retrospective, Q=Questionnaire, L=Longitudinal, rel=relative, pt=patient, DDS=doctors deputising service HCP= health care professional, C=Cancer, NnC=Non-cancer, H=Hospice, GPH=GP hospital, Hm=Home, Hspc=Hospice, Prim=Primary study - admissions, Sec=Secondary study -- admissions, PC=Palliative Care, NonPC=Non palliative care, Ix=Investigation, Mx=Management, IP=Inpatient, HF=heart failure, COPD= Chronic Obstructive Pulmonary Disease</p>							

Table 3-1 (continued)

No	Name of Study	Summary of features	Research Method	Main stated aim of study	Site of study	Sample	Main findings related to admission
7	Skilbeck et al 1998	P I NnC Hm Sec PC	In depth qualitative I	Identify COAD dying care needs	Doncaster	63 adv. COAD pts with > 7day admission	Admission with extreme breathlessness. Pts social invisible until admitted or contact GP. Each admission could be last compounded death anxiety.
8	Seamark et al 1998	R S C GPH/Hspc, Sec PC	Medical case note review	Compare palliative care in Hspc vs GPH	All GPH Devon and Hospice in Exeter	Final admissions from death certificate 171 GPH and 116 hospice	Admission - Community hospital vs hospice: Curative or active Rx 4.1% vs 0%, Ix 4.7% vs 0.1%, Pain control 11.1% vs 24.1%, other symptom Rx 15.2% vs 39.7%, social reasons 12.9% vs 10.3% terminal care 44.4% vs 20%. Rehabilitation 7.6% vs 4.3% GPH pain and symptoms less likely. Faecal incontinence more.
9	Skilbeck et al 1999	P Q C/NnC H Sec PC	Nurse completed questionnaire	Identify pall care pts ?suitable for SPCU	Teach hospital Sheffield	Pt considered terminal by ward on 2 days	47pt 5% of inpatients (25% terminal 60% palliative 15% both) Source: 35% GP, 23% A/E, 32% elective or transfer. Reason: 20% deterioration, 24% symptom Mx, 16% Ix, 18% surgery, 19% other.
10	Rhodes and Shaw 1999	R I C/NnC Hm Sec PC	In depth qualitative interview	Insight into caring for dying relative	Yorkshire HA area	33 pts from death cert	Admission: Pain > distress in pt and care, 18 hosp death - 5 admission last hours or days - rapid deterioration. Rel could not cope with care BUT some fear of witnessing death or living in death house. Place of death less important than manner of dying.
11	Lecouturier et al 1999	R Q rel C Hm Sec PC	Retrospective post Q.	To assess carer satisfaction with services	South Tyneside	355 carers of patients identified as dying from district death cert	Response rate 44%. 92% admitted to hospital overnight in the last year. 59% for symptom relief, 41% diagnosis, 14% curative treatment. 24% felt more could have been done in community.
12	Gore et al 2000	P L MM C/NnC Hm Sec PC	Multi-method. I and QoL tools	To compare QoL and satisfaction	Hull. Lung / radiotherapy clinic	50 COPD pt 50 NSCLC Cancer	COPD pts significantly more emergency adm largely acute exacerbation. NSCLC visit GP more with new symptoms.
13	Oliver 2001	P I NnC Hm Sec PC	In depth interview	Explore perceptions + needs in COPD	Community	16 pts 1/2 GP care and 1/2 hosp care	The limitations of the GP - patient relationship may contribute to failure to seek early medical advice > emergency admission to hospital.

Abbreviations used in table: P=Prospective, R=Retrospective, I=Interview, Q=Questionnaire, L=Longitudinal, rel=relative, pt=patient, DDS=doctors deputising service
HCP= health care professional, C=Cancer, NnC=Non-cancer, H=Hospice, GPH=GP hospital, Hm=Home, Hspc=Hospice, Prim=Primary study - admissions, Sec=Secondary study - admissions, PC=Palliative Care, NonPC=Non palliative care, Ix=Investigation, Mx=Management, IP=Inpatient, HF=heart failure, COPD= Chronic Obstructive Pulmonary Disease

¹ Non small cell lung cancer patients - possibly earlier in course of illness cf COPD.

Table 3-1 (continued)

No	Name of Study	Summary of features	Research Method	Main stated aim of study	Site of study	Sample	Main findings related to admission – isolated from other findings which give context and will be discussed in the text
14	Sidell and Komaromy 2003	HCP MM C/Nc NH Sec PC	Multimethod NH study	Review pall care in care homes in UK	NH in UK	100 interviews. 12 obs studies	Keen to keep pts. Problems: predicting terminal phase. relative pressure, skills/equip, GP decision, 22% NH pt die in hosp. ²
15	Boyd et al 2004	P L I Hm NnC Sec PC	Longitudinal. Qualitative interviews	Pt and care views on health/social	HF pts urban SE Scotland	20 patients carers and HCP	Progressive decline + acute exacerbation led to hosp admission. Some said late GP action led to admission. Last admission multi-causal / rel unable to carry on caring.
16	³ Clare et al 2004	P O H Prim C/NnC PC	Prospective observational	Review reasons for hospital admission	Leeds teaching hosp	394 pt referred for pall care. 14 NnC	Reason: Symptom Mx 53%. Planned Ix/Mx 31%. Acute – no previous diagnosis 14%. 2pts lack of community service. 50% alive 1 month.
17	Horne and Payne 2004	P I Hme NnC Sec PC	Semi-structured interviews	Explore experience identify need HF	Doncaster pt homes	20 pts recruit by cardiologist/ geriatrician	Breathlessness associated with fear primary reason for calling ambulance or GP. Fear of readmission prominent.
18	⁴ Aldred et al 2004	P I Hme NnC Sec PC	“Focused” interview	Explore impact of HF on older pts	UK DGH int in pts home	10 pts >age60 joint 1 pt + carer	Carer inability to cope led to hospitalization. Fear of calling GP or DDS as would lead to admission.
19	Exley et al 2005	P L I Hme C/NnC Sec PC	Qualitative I ⁵ Pt/carer + bereaved rel	Establish needs of cancer vs NnC	2 GP practices Leicestershire	16 cardio-respiratory disease 11 cancer	NnC – numerous admissions over years with range of conditions. C admissions over shorter periods for symptom control.
20	Worth et al 2006	P I Hme C Sec PC	Interviews and focus groups	Explore experience + perspectives of OOH care	3 Co-ops in SE Scotland	32 pts recent OOH contact – carers + HCP.	Fear admission, tried to avoid it. Most of 8 admitted considered it appropriate. Concern, unfamiliar GP led to admission. Others preferred call ambulance due to poor experience. GP said “lack time, easier to admit.”

Abbreviations used in table: P=Prospective, R=Retrospective, I=Interview, Q=Questionnaire, L=Longitudinal, rel=relative, pt=patient, DDS=doctors deputising service
HCP= health care professional, C=Cancer, NnC=Non-cancer, H=Hospice, GPH=GP hospital, Hm=Home, Hspc=Hospice, Prim=Primary study - admissions, Sec=Secondary study – admissions, PC=Palliative Care, NonPC=Non palliative care, Ix=Investigation, Mx=Management, IP=Inpatient, HF=heart failure, COPD= Chronic Obstructive Pulmonary Disease

² Cited in Katz IJPN 1999 5: 58

³ Conference abstract only

⁴ Used modified schedule of Horne. Pt elderly but mean age = 74 Horne 73

⁵ Interviews described as “free flowing” to allow description of experience. Chose “good practices” to be able to compare disease rather than poor practice

Table 3-2 - Reasons for Admission - Issues Emerging

Patient Reason	Professional Construction	Contextual comments
<p>Feeling of safety in hospital²⁰</p> <p>Poorly controlled symptoms¹⁰</p> <p>Extreme SOB^{7 17}</p> <p>Collapse⁶</p> <p>GP had not acted fast enough to prevent admission¹⁵</p> <p>Doctor's decision. (Sometimes with patient reluctance)¹⁸</p> <p>Calling ambulance:</p> <ul style="list-style-type: none"> - GP not available⁶ - Preference²⁰ <p>Fear – call GP or ambulance¹⁷</p>	<p>Symptom Mx^{1 2 3 5 8 9 11 16}</p> <p>Terminal care^{2 3 4 8}</p> <p>Investigation^{1 2 5 8 9 11 16}</p> <p>Treatment^{1 2 5 8 9 11 16}</p> <p>Diagnosis¹¹</p> <p>Social reasons^{1 3 5 8}</p> <p>Nursing needs¹</p> <p>Acute deterioration^{12 15}</p> <p>Lack of community services¹⁶</p> <p>Admitted for acute care – redefined as palliative^{9 16}</p> <p>Admitted with co-morbid condition¹⁵</p>	<p>Isolation of patients^{1 4}</p> <p>Invisible patient until crisis (esp Non Cancer > crisis admission)^{7 19}</p> <p>Lack of social support¹⁵</p> <p>Increasing length of palliative phase³</p> <p>Worsening symptoms³</p> <p>Weakness³</p> <p>Worsening quality of life³</p> <p>Increasing social needs¹⁵</p> <p>Multiple co-mordity¹⁶</p> <p>Balancing need against wish to avoid it²⁰</p> <p>Absence of stoicism of carer³</p> <p>Patient / carer unrealistic expectation regarding prognosis³</p> <p>Difficulty diagnosing terminal phase in community^{14 15}</p> <p>Pt admitted with no previous diagnosis – found to have terminal cancer¹⁰</p>
<p>Carer Reason</p> <p>Fear of condition in carers¹⁰</p> <p>Family insistence – something must be done^{10 14}</p> <p>Exhaustion^{1 4}</p> <p>Fear of having “death in the house”^{3 10}</p> <p>Inability to cope^{15 18}</p>	<p>Key to Table:</p> <p>The issues emerged from the data in the studies. The number of the study (from Table 3-1) is given next to the issue listed.</p>	<p>Variable service ability to keep patient at home/NH¹⁴</p> <p>Mx of pt by hospital physician rather than GP > recurrent admission.¹⁹</p> <p>Poor doc/pt relationship may lead to pt failing to consult until crisis.¹³</p> <p>GP holds power¹⁴</p> <p>Lack of communication – Primary and Secondary care¹⁸</p> <p>Inevitability of admission (in patient's mind) if GP called esp. DDS¹⁸</p> <p>Lack of time acknowledged by OOH docs to lead to admission more likely²⁰</p> <p>Lack of GP knowledge the patient OOH²⁰</p>

There is overlap across these categories. For instance ‘carer exhaustion’ (carer reason) might be categorised as ‘social reasons’ (professional construction), or ‘increasing social needs’ (contextual factors). Such categorical definitions may not be precise and how they are employed may differ between studies or between researchers within a study. I have not attempted to collapse individual given reasons further, since the lack of clear definition and the richness and complexity which would be lost in the process was judged to preclude this as a satisfactory course to take.

3.6 Findings

3.6.1 Characteristics of included papers

Note: 1) The numbers in brackets in the text relate to the number of the paper as given in Table 3-1.

Note: 2) The characteristics of papers fulfilling inclusion criteria are summarised in Table 3-3.

Twenty studies of varied design and purpose which fulfilled the criteria for inclusion were retrieved (summarised in Table 3-1). Only two studies had a primary aim of directly reviewing reasons for admission of palliative care patients (3, 16) with one additional study reviewing reasons for admission of a general population, commenting specifically on terminal care (4). The other studies presented useful data on reasons for admission but the primary aim of the studies were broader: including exploring the palliative care needs in general for a group of patients, where need for hospital admission was considered a relevant factor (7, 10-15, 17-19), surveys into place of death (1, 2, 5, 6), surveying palliative care received in hospital (8, 9) and exploration of out of hours services (20). Nineteen studies surveyed specific patients (1-13, 15-20) either directly or through a proxy (relative or health care professional), twelve of these collecting data prospectively (2-4, 7, 9, 12, 13, 15, 16-19) and seven retrospectively (1, 5, 6, 8, 10, 11, 20). The remaining study systematically surveyed the experiences of health care professionals in nursing homes, but did not focus on specific patients (14). Five studies were longitudinal in which patients were investigated over a variable time period (2, 3, 12, 15, 19). Nine studies used qualitative interviews, exploring relevant experiences, interpretations

and opinions (7, 10, 13, 14, 15, 17-20), whilst 11 were quantitative surveys reporting on numbers and proportions of patients with varying reasons for admission (1-6, 8-9, 11-12, 16).

Eight studies involved cancer patients (1-3, 5, 6, 8, 11, 20), five non cancer patients (7, 13, 15, 17-18) and seven both cancer and non cancer patients (4, 9, 10, 12, 14, 16, 19), although only two of these latter studies specifically compared reasons for admission between cancer and non cancer patients (12, 19). All of the studies which included non-cancer patients were concerned with cardio-respiratory disease, which exactly corresponds with the ‘organ failure’ categorisation in terms of illness trajectories in palliative care (Lunney et al. 2003; Murray et al. 2005). Therefore no studies specified that they included specific patients falling into the ‘frail’ category, i.e. older patients with conditions such as dementia undergoing gradual decline; however the nursing home study (14) is likely to refer to this type of patient. It is possible that the community hospital study (4) does include patients in this latter category, although this is not explicit. All but one of the studies (4) specifically concerned palliative care patients.

Type of Study N=20	Methodology	Patient group	Reasons for admission of focus
Retrospective = 8	Qualitative =10	Cancer = 8	Primary = 2
Prospective = 12	Quantitative = 10	Non Cancer = 5	Secondary = 18
		Both = 7	
	(Longitudinal = 5)		

Table 3-3 - Summary Characteristics of studies fulfilling selection criteria

A number of other studies which describe the issues facing cancer and non-cancer palliative care patients or comparing non cancer and cancer patients have been published, many quite similar to the studies included, but these contained no data on reasons for admission therefore they were excluded from the study.

The two papers with the primary aim of describing reasons for admission of palliative care patients are quantitative. Hinton (1994b) is a seminal study surveying longitudinally the experience of patients and carers who were receiving the St Christopher’s home care service. In this paper Hinton presents the characteristics which are associated with patient admission from home care. In the second study Clare et al. (2004) survey the reason for admission in patients who have been

referred to a hospital palliative care team. This was a poster presentation from the UK Palliative Care Congress and therefore limited in the data given. However, Skilbeck et al. (1999), whilst not primarily concerned with reasons for admission, do present similar data from a survey of palliative care patients admitted to a large teaching hospital. In common with other papers reporting quantitative studies, the reasons for admission in these studies are largely given in terms of professionally constructed categories (Table 3-2). Two retrospective surveys of cancer deaths from the same team give data on reason for admission to acute hospital beds (Seamark et al. 1995) and GP hospital beds, comparing the latter with reasons for hospice admission (Seamark et al. 1998b).

For other studies - in which admission is discussed but is not the primary focus of the study - descriptions of reasons for hospital admission are often restricted to comments such as:

‘the numbers of emergency admissions and GP visits per year differed between the groups, with the COPD patients having significantly more emergency admissions per year (largely due to exacerbations)’ p1003 (Gore et al. 2000).

Other papers do give more detail about hospital admission although this is often fragmentary and not necessarily intended by the authors to be linked together. For instance Boyd et al. (2004) describe reasons for hospital admission in three separate sections of their paper.

‘We found that people living with advanced heart failure described a pattern of progressive decline punctuated by episodes of acute deterioration and admission to hospital, growing dependence and an unpredictable terminal phase’ p587.

‘Others complained that their general practitioner did not act quickly enough to prevent hospital admission’ p588.

‘A final admission to hospital was as likely to be due to a non-cardiac condition or increasing care needs beyond the capacity of informal carers and community services to cope’ p589.

In these papers, since the primary aim of the studies were not to describe reasons for admission the issues relating to this are not generally described in any depth.

However, in the majority of these papers, useful contextual information such as:

social isolation, difficulty in accessing necessary services and the strains apparent on the family carer is included which does aid an understanding of which factors might be of relevance.

3.6.2 Reasons for admission

The reasons for admission arising from the papers in this review can be grouped into the following categories: non cancer patients and cancer patients – the common categorisation used in palliative care; care homes, and community hospitals - as representing specific caring sites. For each category I will briefly present background literature before discussing the emergent issues from the identified papers. Finally, I will discuss contextual issues arising in community services which affect reasons for admission such as attitudes of health care professionals and availability of services. Whilst all of the data relating to admissions will be drawn from the twenty studies identified, papers presenting background information which clarifies context or supports or challenges emerging issues will be utilized.

3.6.3 Non cancer patients

3.6.3.1 Background

As a group, patients with organ failure tend to have a higher average age than cancer patients (Addington-Hall et al. 1998b; Murray et al. 2002; Lunney et al. 2003). In addition, prediction of prognosis is particularly difficult in patients with organ failure (Fox et al. 1999) since the trajectory followed by patients in terms of functional impairment is typically one of slow decline punctuated by acute exacerbations of disease, the outcome of which may be death or improvement back towards the chronic status (Murray et al. 2005). Being older these patients are particularly likely to have high levels of co-morbidity and have older people caring for them who may themselves be in poor health (Aldred et al. 2005). In addition, they often suffer social isolation (Skilbeck et al. 1998) with comparative studies reporting that they are less likely to have nursing support at home than cancer patients (Edmond et al. 2001; Murray et al. 2002; Exley et al. 2005). Care may be poorly co-ordinated between secondary and primary care with patients unsure of how to access help when needed (Aldred et al. 2005). There seems to be a remarkable similarity in terms of clinical and social context between COPD and heart failure patients and Exley et al. (2005) do not distinguish between these groups

in their study. Skilbeck et al. (1998) describe the COPD patient in the following way:

‘There is a sense in which these people are socially invisible until they require symptom management in an acute phase of the illness, involving either contact with the GP or admission to hospital’ p253.

3.6.3.2 Reasons for admission

The majority of studies of patients with cardio-respiratory disease identified comment that admission is often recurrent as a result of acute breathlessness or exacerbation of the patient’s underlying clinical condition (Skilbeck et al. 1998; Gore et al. 2000; Boyd et al. 2004; Horne and Payne, 2004). However, Exley et al. (2005) report that although admissions are recurrent, often over a number of years, they may be for a variety of conditions. Similarly Boyd et al. (2004) comment that final admission in their study was as likely to be related to a non cardiac condition or increasing care needs. Aldred et al. (2005) also observe that hospitalization was likely to result from the carer’s inability to cope.

Most of these studies discuss the reasons for admission in general terms although Horne and Payne (2004) make the point:

‘Breathlessness was often associated with fear and the primary reason for calling out the doctor or an ambulance’ p294.

This however is the only direct comment regarding a trigger for admission in non cancer patients, although fear and anxiety associated with breathlessness is reported as a prominent emotion (Skilbeck et al. 1998; Boyd et al. 2004).

3.6.3.3 Discussion

That chronic cardiopulmonary disease leads to recurrent admission and present a high burden on acute resources is well known (Lyrtzopoulos et al. 2005). The National Services Framework (NSF) for coronary heart disease (DH, 2000a) aims to reduce both the morbidity associated with acute exacerbations and the number of emergency admissions related to them. Studies have demonstrated that specialist home care teams can be effective for reducing admission rates in COPD (Ram et al. 2004) and in heart failure, with reduced frequency of exacerbations, improved survival and improved quality of life (Stewart et al. 1999; Blue et al. 2001). Only

one paper in this review commented that a specialist nurse was available for a few patients (Boyd et al. 2004); although most of the studies do not comment specifically. Horne and Payne (2004) propose that such a services would be desirable for providing support for the heart failure patients in their study.

3.6.4 Cancer patients

3.6.4.1 Background

Whilst cancer patients are more likely than non cancer to have received DN services, the level of specialist service available in the community to cancer patients is known to be highly variable (Hockley, 1997; Ahmed et al. 2004); with older patients less likely to receive either palliative care CNS services (Addington-Hall et al. 1998a) or be admitted to hospices than younger patients (Addington-Hall and Altmann, 2000; Grande et al. 1998). Cancer patients are more likely to receive CNS services than non cancer patients, however, although as a group they have a younger average age than non cancer patients age is not the determining factor for this difference (Addington-Hall and Karlsen, 1999). Variations in the levels of service received by cancer patients with different disease types have also been noted. Patients with haematological malignancy and brain tumours are less likely to receive palliative care CNS services (Addington-Hall and Altmann, 2000) whilst patients with breast and colorectal cancer are more likely to receive inpatient hospice care (Addington-Hall et al. 1998a). The reasons for these group differences are undoubtedly complex with varying types and levels of need in each group; further research is needed in understanding these factors (Burt and Raine, 2006).

3.6.4.2 Reasons for admission

Unlike non-cancer patients the reasons for admission for patients with cancer seems more variable. Pain is a prominent symptom mentioned as a trigger for admission, but a number of other symptoms may be implicated (Hinton, 1994b; Seamark et al. 1995; Lecouturier et al. 1999; Clare et al. 2004; Skilbeck et al. 1999; Rhodes and Shaw, 1999). Hinton comments that he was unable to distinguish particular patterns of symptoms associated with admission despite weekly interviews with 77 patients and their carers in a prospective longitudinal study.

Hinton's study gives particularly valuable insights into issues influencing the need for admission. The period before admission was typically associated with increasingly troublesome symptoms, weakness and declining quality of life for the patient and increasing fatigue for the carer. In addition the longer patients were receiving the hospice home care service the more likely they were to require admission, although the reason for this was not entirely clear. Patients who expressed more optimism and who seemed to be avoiding their true prognosis at the outset were more likely to be admitted as their condition deteriorated. Carers showing acceptance of their prognosis and displaying a stoical attitude were more likely to keep a patient at home through the whole course.

The interplay of symptoms and social and attitudinal factors are also apparent in Rhodes and Shaw's (1999) study of 33 bereaved carers, conducted as a needs assessment with cases selected from death certificate records. Some patients received services from Macmillan nurses and others received no community specialist support. Poor pain and symptom control were cited as being a common reason for admission in the later stages of the illness. Admissions were often initiated by carers who were not only themselves distressed by the patient's suffering but also were having to cope with practical aspects such as disturbed nights and poor sleep. They comment:

'Few [carers] had anticipated the level of care which would eventually become necessary' p43 (ibid).

Many admissions a few days before death were triggered by rapid deterioration in the patient's condition and the carer feeling unable to cope. Whilst Rhodes and Shaw acknowledge that better symptom control and support could have prevented some of these admissions they add:

'Closer questioning, however, sometimes revealed deeper, underlying fears of witnessing the death alone or of living in the house in which the person has died' p47 (ibid).

Not surprisingly similar concerns were also expressed by carers in Hinton's (1994b) study and elsewhere (Barritt, 1984).³

Three studies identified the need for urgent admission in patients who were in or entering the terminal phase (Seale and Kelly, 1997; Hinton, 1994b; Rhodes and Shaw, 1999). Hinton describes patients, particularly those who had earlier expressed a 'fighting spirit' experiencing a 'late flurry of admission' p209 (Hinton, 1994b). Seale and Kelly (1997), comparing hospice and hospital deaths in a retrospective comparative case study with carers for 33 patients being interviewed in each arm, describe how hospital admission resulted from urgent GP call (30%) or ambulance call (36%), whilst hospice admission involved no urgent GP calls and the ambulance was called for only one patient; this suggests that hospice admission was more likely to be planned and controlled than hospital admission.

Quantitative studies of patients who have been admitted to hospital are able to show the proportion of palliative cancer inpatients who have been admitted by various routes and for differing reasons. Skilbeck et al. (1999) found that of 93 palliative patients identified on two days in a 1200 bed teaching hospital, 35% had been referred by their GP and 23% via A/E. The rest included those awaiting surgery (presumably elective admissions) or who had been transferred from other hospital. Twenty four percent had been admitted because of a deteriorating condition, 17% for symptom control and 23% for 'acute investigation'. However, Clare et al. (2004) surveying 394 referrals to the hospital palliative care team in another teaching hospital (14 of whom were non cancer), report that 53% were admitted for symptom management or assessment and 31% for planned investigation or treatment. Lecouturier et al. (1999), in their post bereavement carer study report that 59% of admissions had been for symptom control. All three studies identified another group who had been admitted as emergencies but were not known to be palliative on admission, although subsequently were found to be so. Lecouturier et al. (1999) identified this for 41% of admissions and Clare et al. (2004) for 14%, whilst Skilbeck et al. (1999) encountered this situation they gave no figures, but remarked:

³ Barritt (1984) whilst otherwise fulfilling the criteria is not included in the systematic review as the study was published before 1990.

‘On many occasions admission to hospital had initially been for an acute problem, which had subsequently become defined as requiring palliative support’ p113.

Clare et al. (2004) report that only 2/394 were admitted due to a lack of community services. This is surprising even if this area was extremely well provided for, since high levels of need and rapid changes in patient condition will occasionally overwhelm even the best services. One explanation might be that these two patients were admitted for lack of community services *only*, i.e. there were no *clinical* problems justifying admission. In view of the complexity of the issues facing palliative patients and their carers, even if lack of community services is a major factor in some admissions, high levels of clinical need in these patients would be apparent to justify hospital admission. Conversely, Herd (1990) in West Cumbria reports that of 157 patients sampled, for 22% admission was triggered by lack of lay carers and in a further 45% because the lay carer was unable to give care.

3.6.4.3 Discussion

Patients may be admitted for complex reasons related to symptom issues, social problems and psychological factors. The reason given for admission may depend on the perspective of the researcher or the participant or be limited to a selection of previously defined responses. This is illustrated by Seamark et al. (1995) who report on a retrospective questionnaire study in which GPs’ and hospital doctors’ opinions on the reason for admission for 1022 patients who died in hospital are noted. Only one reason was allowable, limited to six possibilities: - investigation, difficult symptom control, curative/active treatment, social reasons, management of pain and medical reason unrelated to cancer. Only moderate levels of agreement between the GPs and hospital doctors for individual patients (20 – 57%) are reported. It is interesting to note that for 28% of patients admitted, GPs indicated that death was *not* expected, but this was so for only 12% in hospital doctors’ opinions.

A significant group of patients (14% - 41%) with advanced cancer were admitted before their illness had been diagnosed. This is based on only two studies so further research is needed to clarify the true extent of this type of admission.

3.6.5 Care homes⁴

3.6.5.1 Background

Year on year increasing numbers of older people live and die in care homes (Davies and Seymour, 2002). Residents in care homes are an important group with palliative care needs (Froggatt, 2004) although they are reported as less likely to have access to specialist palliative care than other patients (Davies and Seymour, 2002). Death in care homes is more likely to be from non-cancer diagnoses (Froggatt and Payne, 2006), although the chances of cancer patients dying in care homes increases markedly with advancing years (Lock and Higginson, 2005). The majority of residents in care homes are frail with multiple co-morbidities and 46% are reported as suffering from a 'degree of dementia' p345 (Froggatt and Payne, 2006). The 'illness trajectory' in these residents is therefore likely to follow the 'prolonged dwindling' course p1008 (Murray et al. 2005) marked by a gradual decline of health and functioning over months or years. Since the disease patterns and needs of care home residents are markedly different in comparison to hospice patients the dominant model of specialist palliative care is not directly transferable to this setting (Froggatt, 2001).

Reducing the number of admissions of care home residents has been a major aim of the End of Life Programme (EoLCP) of the NHS (NHS, 2004). Katz et al.(1999) reporting from a UK wide survey of care home residents state that 22% of 2180 deaths occurred in hospital. Similarly a more recent study in one county reported a 29% hospital death rate (Froggatt and Payne, 2006). Few UK based studies have examined the specific reasons for hospital admission of care home residents. Godden and Pollock (2001) reported from a population based study in South London that the relative risk of admission for care home residents compared to those in the community was 1.39 for all diagnoses and 3.96 for fractured neck of femur. The relative risk of dying in hospital was 2.58 for those admitted from care homes. Hospital admissions for acute medical or surgical conditions may be entirely

⁴Care homes until the 2000 Care Standards Act were distinguished as either residential or nursing homes. The majority of these institutions are in the private sector, increasingly managed by larger corporate organisations. A smaller number are managed by local authorities and voluntary sector organisations (Davies and Seymour, 2002).

appropriate; without studies specifically examining reasons for admission, the proportion of admissions which might be considered unnecessary will be unknown.

3.6.5.2 Reasons for admission to hospital

Sidell and Komaromy (2003) present the only study of reasons for hospital admission for this group which I could identify. They highlight some general issues emerging from interviews with managers of 100 care homes⁵ rather than presenting data concerning specific admissions. Strong feelings were expressed that residents should remain in the care home if at all possible to be nursed by the staff they knew in their own familiar surroundings. Hospital admission they believed could be detrimental to the older person's mental state and could lead to residents dying prematurely or suffering over-investigation. These were important contextual issues surrounding decisions to admit patients to hospital.

Homes had a variable ability to provide terminal care, particularly over prolonged periods leading to admission of some dying residents. Some residents were admitted for acute conditions thought remediable; however, diagnosing the terminal phase was identified as problematic and clinical uncertainty combined with fear over the potential failure to admit patients appropriately presented a dilemma. Relatives could at times bring pressure to bear for patients to be admitted and on the whole the relatives' view prevailed.

GPs played a key role in decisions regarding admission to hospital and in presenting the case for not admitting residents to relatives. Many GPs were reported as keeping dying patients in the home if they felt that the staff could effectively manage them there; conversely some GPs were reported to make the decisions to admit without discussion with the care home staff, when managers felt that they could have coped.

3.6.5.3 Discussion

Deciding which patients to admit to hospital 'is a complex one which exposes many contradictions' p49 (Sidell and Komaromy, 2003). A multidisciplinary approach between GPs and senior care home staff seems to be a particularly important factor in arriving at the best decision for the patient. In addition, knowing the resident's wishes for care is important. Davies and Seymour (2002) asserted that it is unusual

⁵ Part of the same large UK scale multi-method study as (Katz et al. 1999).

for residents admitted to care homes to have been involved in discussions concerning their future care. This issue is being highlighted and addressed by the EoLCP who have produced guidance for health and social care staff on 'advance care planning' (EoLCP, 2007) and are promoting a care home version of the Gold Standards Framework (EoLCP, 2006). Research is ongoing to evaluate the effectiveness of these interventions in care homes (personal communication Professor Collette Clifford). Further research into the complexities surrounding admission of care home residents to hospital is needed.

3.6.6 Community hospitals

3.6.6.1 Background

Community hospitals are predominantly small and found in rural areas. They enable patients to be managed as inpatients, close to home and by their GP. They have been highlighted as having an important role in providing palliative care (Payne et al. 2004; Thorne et al. 1994; Seamark et al. 1995) with some community hospitals having palliative care units attached (Lloyd-Williams, 1996). The availability of community hospitals has been found to be associated with fewer palliative patients dying in acute hospital beds (Thorne et al. 1994). Carers have reported high levels of satisfaction with the care dying patients received in such institutions in comparison with district hospitals (Hawker et al. 2006), although less satisfaction in comparison to hospices (Seamark et al. 1998a).

3.6.6.2 Reasons for admission

Seamark et al. (1998b) report on a study comparing the final admission (i.e. ending in death) for 171 terminally ill patients to several community hospitals with 116 similar admissions to a single hospice. Fewer patients were admitted for symptom control to the community hospital compared to the hospice, with more patients being admitted for terminal care. Interestingly 8.8% of patients were admitted to GP hospitals for investigation or active treatment who then became terminal, with only one such patient admitted to a hospice. The authors conclude that:

'These findings probably reflect specialist versus generalist usage of these beds and the traditional hospice service role of symptom control' p1314 (ibid).

Seamark et al.'s study gives no indication of the proportion of total admissions to GP hospitals which are for palliative care cancer patients. However Tomlinson et al. (1995) in a general survey of 685 consecutive admissions to community hospitals in Leicestershire, report that 10% of patients had malignancy, 6% were admitted for terminal care and a further 3% for respite care. However, of the 25% with cardiovascular disease no indication is given of how many had palliative care needs. The authors also report that 44% of admissions were due to the inability of relatives to cope with continued caring; however the proportion who were palliative was not reported.

3.6.6.3 Discussion

Although community hospitals are important places where palliative patients receive care, little is known of the reasons for admission to these units. One problem with interpreting the studies identified is that no indication is given as to the number of patients admitted as emergencies. In fact Seamark et al. (1998b) report that 25% of patients admitted were transferred from acute hospitals, with the overall figure for Tomlinson et al. (1995) being 15% (i.e. not specifically palliative care patients). Of those admitted from home a number may well have been urgent, but the relationship between GP and community hospital is different from that between GP and district hospital where the majority of admissions for palliative care patients seem to be emergencies (Skilbeck et al. 1999). Further research regarding reasons for admission to community hospitals for palliative care patients, particularly how these differ from admission to acute hospitals is needed.

3.6.7 Community services and admissions – contextual issues

For both cancer and non cancer patients the availability of community services and the competence and attitude of health care professionals were reported as important factors. I will therefore explore some of the contextual issues which influenced the reasons for admission to hospital (Table 3-2 page 107).

Skilbeck et al. (1999) reported that GPs were involved in 35% of palliative care emergency admissions although 23% were admitted through A/E, with Seale and Kelly (1997) reporting that for cancer patients who died in hospital, similar numbers had been admitted following GP and ambulance calls.

Many of the comments regarding the role and availability of GPs revealed problems. Poor information and communication might lead patients to be unclear about who to call in an emergency situation (Aldred et al. 2005), conversely others reported difficulty with accessing their GP when necessary (Rhodes and Shaw, 1999). Oliver (2001) examined the perceptions and needs of patients with COPD, who as regular users of the service sometimes showed evidence of difficulties in maintaining a healthy doctor patient relationship. This could lead to them failing to seek early medical advice which could lead to avoidable emergency admission. In Boyd et al.'s (2004) study, some heart failure patients considered that hospital admission could result from their GP having failed to act quickly enough in a deteriorating clinical situation, however Aldred et al. (2005) reported that some patients with heart failure were ambivalent about calling a GP, feeling that this would lead to automatic admission which they did not want. Cancer patients and their carers in Worth et al.'s study (2006) into out of hours GP services had similar concerns about calling a GP, although most of the patients who were admitted out of hours felt that this had been an acceptable outcome.

Reviews of out of hours periods have indicated that they do present a particularly problematic time for accessing emergency medical care, e.g. Salisbury (2000) and Thomas (2000). Lecouturier et al. (1999) report that of 156 cancer patients who died, relatives indicated that '92% had been admitted overnight to hospital at some time during the last year of their life' p281. This seems to be a very high figure for out of hours admissions, considering that the sample was taken from death certificate records and should therefore not have been over represented by patients with particularly complex needs. Reasons for this are not given by the authors and since no similar post bereavement population based quantitative studies in palliative care patients report on night time admissions, it is not possible to compare this with other studies.

Worth et al. (2006) give valuable contextual insights which aid understanding of the complexity surrounding emergency admission out of hours. The authors highlight that this is a time of great anxiety for patients and their carers, who had difficulty in deciding whether a call was justified, had to negotiate a potentially hostile triage system and worried about the quality of service which they would receive. These

fears were based on poor experiences of calling in the past, hearsay or fear of the unknown. Concern was expressed by patients and carers over the service or professionals having little or no information about the patient's clinical condition, leading to anxiety that this might make hospital admission all the more likely. Others expressed a preference for calling an ambulance, reasoning that they would be safer off in hospital rather than seeing an unfamiliar doctor. However, whilst some patients and carers were dissatisfied, others reported high levels of satisfaction with the out of hours service they received.

Worth et al. (2006) also interviewed health care professionals in this study. Doctors expressed concern regarding lack of information and some reported that lack of time to assess needs could be 'a contributory factor in admissions out of hours' p11. Professionals universally considered a specialist telephone advice service to be of importance, echoing the findings of our earlier study, in which co-operative medical directors considered specialist advice potentially valuable in avoiding out of hours hospital admissions (Munday et al. 2002).

Interestingly none of the studies identified discussed the role of other community services in emergency admissions. Rhodes and Shaw (1999) revealed that bereaved carers of cancer patients reported that night sitting services were of great benefit to them and although some carers accessed very few formal services 'the knowledge that it was available gave them confidence and security' p47 (ibid). Whilst the effect of night sitters on hospital admissions remains speculative, such a service would be likely to have decreased relatives' inability to continue caring, which has been reported as a causal factor for admission Herd (1990). An RCT however failed to show that hospital at home services increase home death rates although the authors did not comment on the effects on hospital admissions directly (Grande et al. 1999).

3.7 Discussion

Hospital admission of palliative care patients in the UK occurs for many complex reasons. Non-cancer patients generally have poorer service provision in the community than cancer patients and are frequently admitted for acute exacerbation of disease or because of co-morbidities. Admission of palliative care cancer patients may occur for symptom control, acute investigation, or for social reasons or any combination of these. Since patients may be admitted several times in their final

illness, further research including cohort studies where the experiences of palliative care patients, mapping out their illness course, would facilitate insights into patterns of admission.

Evidence suggests that local patterns of admission vary according to services which are available such as a community hospital. However, little is revealed in this review of the effects of DN and specialist palliative care nursing or night sitting services on admission patterns. Whilst additional services might reduce admissions, the configuration of those services is likely to be important. Evidence from other studies suggests that specialist teams manage *fewer* home deaths if they have access to specialist beds (Grande et al. 1998). Hinton (1994b) seems to support this showing only a 29% home death rate despite a robust hospice at home service. His findings may not describe well the experiences of patients who are not receiving such a specialist service.

Whilst GPs are involved in arranging emergency admissions for a proportion of patients, admission through A/E without GP involvement is also common. Reports from several studies suggest that GPs' approach and attitudes play an important role in the likelihood of admission. Interventions such as the Gold Standards Framework (GSF) may help to increase the effectiveness of primary care teams in delivering palliative care, although our own evaluation of Phases 3 – 6 of the GSF was not able to demonstrate an effect on emergency admissions (Dale et al 2007).

Research into the emergency admission of unselected adult patients to hospital has focused on the appropriateness of the admission, with many studies using specific tools to enable this to be measured quantitatively (McDonagh et al. 2000). Whilst these studies have been useful in defining the need for alternative services such as urgent outpatient clinic appointments (Campbell, 2001), very few have examined the issues of admission from the patient's perspective, which has been acknowledged as a serious omission (Glasby and Littlechild, 2000).

3.7.1 Methodological issues

This is the first systematic review of reasons for emergency admission of palliative care patients to be undertaken. Including qualitative as well as quantitative studies has enabled the complexities and contextual factors reported in the literature to be

explored. Including only UK literature has enabled issues relevant to this country with its unique health service to be explored and has avoided inferences being drawn from other systems which might not apply.

Very few studies have examined the reasons for admission of palliative care patients in detail and it has been necessary for this review to draw on studies with wider aims to access what is known about hospital admissions. For this reason data regarding emergency admission were often ‘buried’ within the identified papers where the primary aim of the study was to report other aspects of palliative care. This makes it possible that further papers containing relevant data may not have been discovered and included.

Variation in definitions used between different studies makes comparison difficult to undertake and few studies give a detailed description of the methods used for collecting data regarding reasons for admission. None of the qualitative studies had the primary aim of surveying emergency admissions, so whilst some do explore the complexity surrounding admission, especially contextual factors, few actually examine the triggers, ‘why has admission occurred now?’ or process, ‘who arranged for the admission and how did it occur?’

3.8 Conclusion

Whilst this review has discovered a limited number of studies describing patient and carer experience of emergency admission and the complex contextual issues which surround it, no study exploring palliative care patient experiences in detail has been reported in the literature. In Chapter-5 I will present a study which explores the reasons for admission of both cancer and non cancer palliative care patients into a district general hospital, particularly concentrating on the triggers and process of admission.

Exploring these issues at the empirical level alone is insufficient, since such an approach will fail to appreciate the extent of the complexity involved. Patients exert choice over which professional or service to call when faced with a need for urgent care, but that choice is not unlimited, it is contingent on the services made available to them. These services will vary in their accessibility and in their appropriateness (either real or in the patient or carer’s perceptions). In addition palliative patients

especially when facing a clinical emergency are relatively powerless, needing to rely on others, with some groups especially so, being almost 'invisible' to community services. Thus choices will be enabled or constrained by wider social issues.

Social structures and issues of power therefore need to be considered when researching emergency admissions. I will use the 'theory of social domains' (Layder, 1997) as a framework to enable an exploration of these issues in Chapter-5. As a prelude to this, in the next chapter I will explore Layder's domains in depth and I will also examine the utility of critical realism as an under-labouring philosophy for palliative care research.

Chapter 4 – Critical methodological pluralism: A framework for palliative care research?

4.1 Introduction

In 1996 Corner published a systematic review entitled ‘Is there a research paradigm for palliative care?’ (Corner, 1996). Emerging with a synopsis of the focus of research in palliative care and the type of methods used, she demonstrated that the commonest examples were descriptive: comprising surveys, retrospective case note reviews and population bases studies; concluding that palliative care had been ‘preoccupied with self discovery’ p206. Symptom and pain control issues formed the commonest subject for research although randomized controlled trials (RCTs) only accounted for 5% of published studies. These were small and frequently underpowered with a median of 34 cases. She suggested that:

‘If studies utilising the gold standard methodologies of the wider health care community are not viable then there is an imperative for palliative care to explore other avenues for its research. This however needs to be undertaken collectively rather than by isolated researchers’ p206 (ibid).

She proposed that palliative care should adopt a flexible approach which was ‘multi-method, multi-perspective, multi-subject and multi-disciplinary’ p208; engaging consumers and practitioners as well as researchers to ensure broad perspectives. Further she suggested that a strategic approach to paradigm development should be taken, rather than it being ‘left to the chance that a Kuhnian revolution might occur’ p207. In this chapter I will explore some of the philosophical and methodological issues which I consider relevant to this strategic approach, suggesting that critical realism gives a suitable philosophical basis for a research paradigm for palliative care and critical methodological pluralism which arises from this could provide the multi-method approach which Corner proposed.

Corner alluded to the ‘gold standard’ methodology of the wider health care community, which according to the evidence based medicine (EBM) movement, is the RCT – designed to evaluate both clinical interventions, e.g. drug therapy and surgical procedures, and health service delivery, e.g. intermediate care services designed to reduce the frequency of hospital admission. RCTs along with other

quantitative research methods: demographic surveys, cohort studies, case-control studies etc, are normally considered as arising from a positivist philosophical position, which has been the dominant stance in biomedical research since the Enlightenment.

The history of the rise and dominance of RCTs however is relatively short and parallels the rise of hospice and palliative care in the second half of the 20th century. As Corner suggests, tensions exist between palliative care and wider health care research around the use of this methodology, which I will argue does not merely relate to practical difficulties with RCTs, but indicates problems inherent in adopting a positivist philosophy when researching a discipline as complex as palliative care.

As in Chapter-2 when I examined the history of community palliative care to gain insights into how this evolved into its present organisational and cultural position, in this chapter I review the history of RCT research linking it with some of the developments in hospice and palliative care research – especially the work of Cicely Saunders - to gain an understanding of the current position of RCTs in EBM and palliative care. Following this I will examine some of the methodological issues regarding RCTs in palliative care specifically.

In the second half of the chapter I will explore the concept of complex causation from a critical realist philosophical perspective. Having set out the general argument for critical realism in this context I will explore some of its developments, particularly the work of Layder and his ‘theory of social domains’ on which I draw in my field research presented in the next two chapters. Finally, I will consider critical methodological pluralism as a critical realist approach for palliative care research.

4.2 Part 1 - RCTs in health services research

4.2.1 Historical perspectives of RCTs

Whilst the roots of RCT research can be traced back through the history of modern medicine from the 19th century to the present day, they were not central to its early rise. A great number of medical syndromes were described through the 19th and early 20th century as a result of observational studies (Porter, 1997). The germ theory of infection was proposed in the late 19th century (Brandt and Gardner, 2000), forming the impetus for the development of antiseptics and then aseptic techniques in surgery.

Developments in neuropharmacology led to the discovery of the local anaesthetic effects of cocaine and subsequently the synthesis of local anaesthetics. Discovery of the general anaesthetic effects of ether and chloroform in the 1840s led to the development of modern anaesthesia, which enabled more complex and invasive surgery to be undertaken (Aitkinson et al. 1993). Medical therapies such as antibiotics, insulin and steroids were introduced in the decades 1920 – 1940 (Le Fanu, 2000). All of these significant advances in medicine were made before RCTs became widely used. Whilst these therapies were often dramatic in their effectiveness, other new treatments were introduced which were subsequently found to be of little or no value. Before RCTs no systematic process for evaluating them existed (Doll, 1998).

New therapies were judged by clinical experience and professional opinion, according to Sir Richard Doll, who qualified in 1937, and this was open to bias. Thus:

‘The treatment of peptic ulcer was, perhaps, more susceptible to claims of benefit than most other chronic diseases; so that in 1948, when I began to investigate it, I was soon able to prepare a list of treatments beginning with each letter of the alphabet. Standard treatments, for their part, tended to be passed from one textbook to another without ever being adequately evaluated’ p1217 (Doll, 1998).

Controlled trials had been proposed as a way of testing the effectiveness of medical treatments at least since the 17th century. One of the earliest records is of a medicinal chemist called Van Helmont, who challenged physicians of his day to demonstrate the effectiveness of blood letting, by casting lots over which treatment patients would receive and then seeing how many died, although it seems this trial never actually took place (Chalmers, 2001). Other examples include James Lind’s trial of the use of citrus fruit for the treatment of Scurvy in the British Navy (Claridge and Fabian, 2005) and Figiber’s randomized controlled trial of serum treatment for diphtheria in 1896 in Denmark (Hrobjartsson et al. 1998). In this study patients admitted on alternate days were allocated to either the treatment or control arm; thus it was probably the first *randomised* trial. Interest in using RCTs in modern medicine followed their successful use by R.A. Fisher in agriculture in the early decades of the

20th century, whose methods were adopted by medical statistician Austin Bradford Hill (Porter, 1997).

Doll describes 1948 as being the watershed for the RCT with two Medical Research Council (MRC) trials published that year, one evaluating the use of streptomycin in tuberculosis and the other investigating whooping cough immunization (Doll, 1998). Both trials used random number tables which allowed allocation to treatment or no treatment to be made on a fully randomized basis (Chalmers and Clarke, 2005).

The development of RCTs was not without opposition particularly from clinicians who were reluctant to countenance treatment decisions being made by chance. However, Bradford Hill's 'understanding of medical susceptibility and medical ethics and ...his concern for simplicity of design and clarity of presentation' p1220 (Doll, 1998) reassured many. D'Arcy Hart, a contemporary researcher reflected that:

'The curative streptomycin trial gave a boost to [Bradford Hill's] views and subsequent teaching, and resulted, after some years, in the present virtually universal use of randomised allocation in clinical trials' p573 (Hart, 1999).

1950 onwards saw a 'golden age' for medical research (Reynolds and Tansey, 2000). Medicine was arguably at a zenith following the promise of antimicrobial therapy to rid the world of tuberculosis and other infectious diseases (Brandt and Gardner, 2000) and the establishment of the NHS with its promise of health care from the cradle to the grave. With funds available from the MRC and other institutions and a 'symbiotic' relationship between the NHS and universities, a freedom existed under which researchers could work effectively with little government interference or control (Reynolds and Tansey, 2000). This came to an end in 1971 with the publication of the Rothschild report which encouraged a more utilitarian process to research stating.... 'the customer says what he wants; the contractor does it (if he can); and the customer pays' cited p634 (Meerabeau, 1996). Rothschild's recommendations were subsequently published in a White Paper and medical research become more centrally and politically directed (Reynolds and Tansey, 2000).

Unfortunately whilst RCT research flourished, patients and the public were at risk with too little attention paid to ethical safeguards for human experimentation within the NHS as well as other institutions. Research was sometimes carried out with no

consent (Booth, 1994), in contravention of the Nuremberg code drawn up following Nazi atrocities in research . Worldwide concern eventually led to the Declaration of Helsinki in 1964 and the establishment of ethics committees for research (Porter, 1997).

4.2.2 Early palliative care research

1948 as well as being Doll's watershed for the RCT and the year of the inception of the NHS was also a significant year for Cicely Saunders, marking the beginning of her quest which was to culminate with the opening of St Christopher's Hospice in 1967 (Clark and Seymour, 1999). Interestingly that year Bradford Hill's team enlisted the help of almoners at St Thomas' hospital, to recruit patients to the smoking cohort study (Le Fanu, 2000). This could have included Saunders who was an almoner there at the time.

Saunders' own research into the care of the dying commenced whilst a medical student, publishing her first paper in the St Thomas's Gazette in 1958. This contains case studies of four terminally ill patients and draws on visits to seven homes for the dying around London. It includes a long discussion section in which she explores the importance of symptom control and well coordinated community care (Saunders, 1958). Clark and Seymour (1999) describe this paper as 'a remarkably far-sighted explosion of ideas which were subsequently to become so central to modern palliative care' p72.

From 1959 Saunders worked as a medical researcher at St Joseph's Hospice in Hackney and during the next decade published over 50 papers describing the nature and frequency of symptoms and modes of therapy for the dying (Clark and Seymour, 1999; Clark, 1998). This work built upon and systematized the concepts and practices described by Worcester (1935), Leak (1948) and Gavey (1952) whom she referenced in her early work (Saunders, 2006). From these early papers it is clear that many of the practices which characterize palliative care were taking shape; for example, the use of regular analgesia for constant pain, the fact that pain is a potent antagonist to any analgesic, the assertion that addiction is not a problem in the terminally ill and the need for close working between general practitioners and almoners in caring for the dying (Saunders, 2006).

Saunders was not alone in conducting observational and survey research. On both sides of the Atlantic during the 1950s and early 1960s various researchers were exploring the use of opioids, neurolytic and regional anaesthetic techniques in the control of cancer pain, whilst the view of pain as a hard wired physiological process was being challenged by exploration of its emotional aspects and the emergence of Melzak and Wall's gate theory (Seymour et al. 2005). Interestingly, researchers in the USA in the 1950s used 'N of 1' studies to test the relative efficacy of various opioids¹ (Seymour and Clark, 2005).

4.2.3 RCTs in early palliative care

In her presentation on 'the treatment of intractable pain in terminal cancer' at the Royal Society of Medicine Section of Surgery in 1963 Saunders explains:

'Although the work has been carried out by a Department of Pharmacology, we have not found that controlled clinical trials are suitable either in this setting or with this particular group of patients. At this stage they have many symptoms, they need a variety of drugs as well as analgesics and their condition is deteriorating, often rapidly. They need a great flexibility of dosage and often have idiosyncracies in regard to the drugs that suit them' p195 (Saunders, 1963) Reprinted in (Saunders, 2006).

However, three years later as the St Christopher's project developed she published a letter in the journal *Geriatrics* outlining the plans for St Christopher's Hospice with inpatient, outpatient and research facilities, which would include RCTs (Clark, 1998). Publishing in the *BMJ* in 1996 she described the rationale for RCTs in the context of early work at St Christopher's.

'We had by that time begun to use diamorphine. There were no controlled trials of this drug to be found, only some clinical reports that it had few side effects. We used it for 42 of our first 500 patients, in women with severe nausea and in a few patients with intolerable feelings of suffocation. By that time we believed that this was the drug of choice, but I realised two things. Firstly, we were getting better and more confident in all that we were doing, secondly, that your

¹ N of 1 studies are considered by the Centre for Evidence Based Medicine to be case reports, i.e. the lowest level of research evidence. Multiple N of 1 may become highest level, as these are counted as multiple cross over trials. http://www.cebm.net/levels_faq.asp#5. (Accessed 07/10/06).

own enthusiasms must be tested. The later work at St Christopher's Hospice by Twycross showed that there was no clinically observable difference between morphine and diamorphine given orally in our setting and with adjuvant treatment' p1600 (Saunders, 1996).

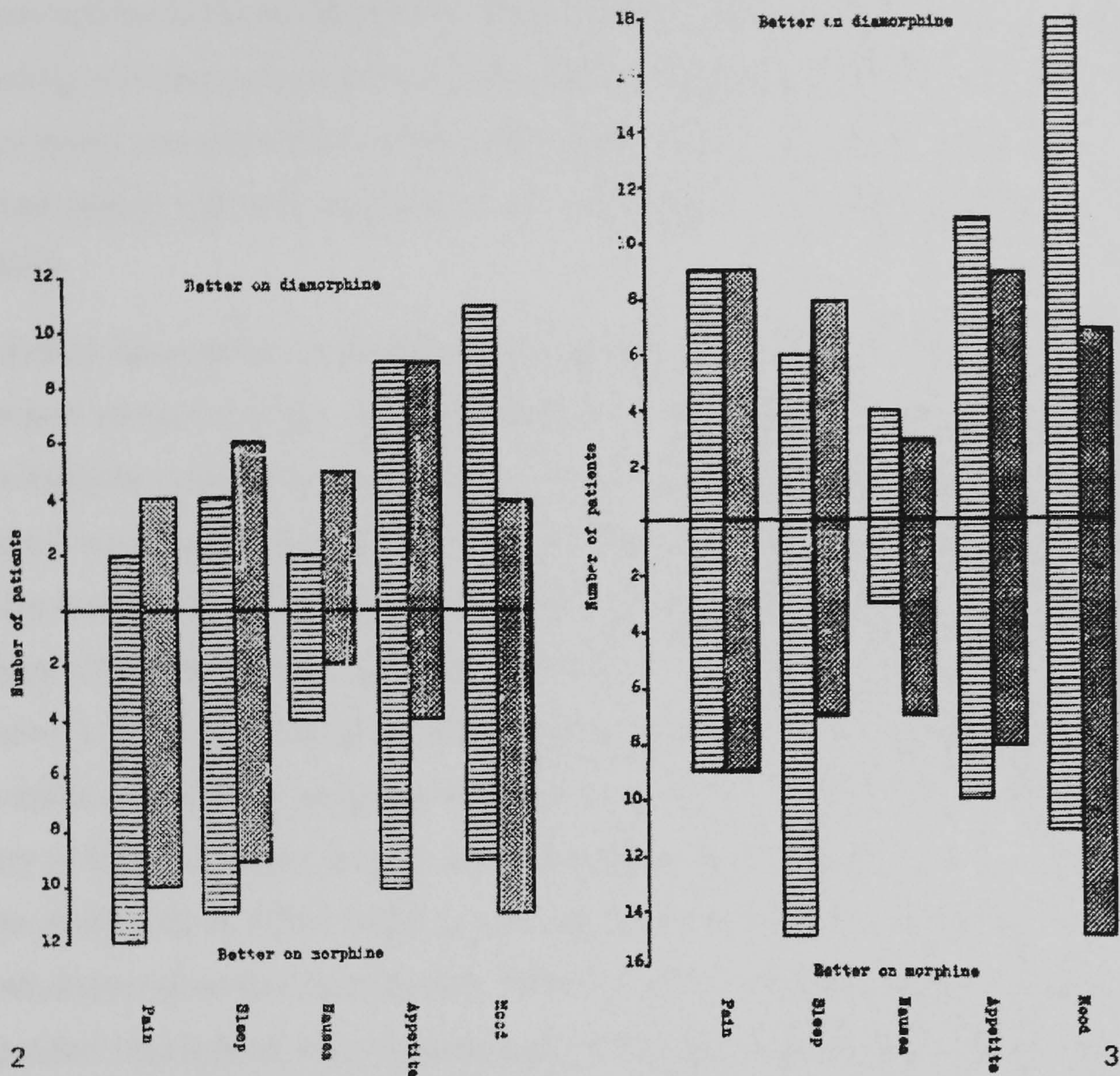


Fig. 2. Non-parametric comparison of male crossover effects. Striped columns diamorphine first; dotted columns, morphine first. Ties excluded.

Fig. 3. Non-parametric comparison of female crossover effects. Striped columns, diamorphine first; dotted columns, morphine first. Ties excluded.

Figure 4-1 - Graph from Twycross (1977)

However, whilst Twycross' study shows no statistical difference in pain control for the population of patients receiving morphine or diamorphine in the trial, it is clear from his paper, that there *was* a clinical difference between the two drugs for some individual patients (Twycross, 1977). In addition, subgroup analysis showed that male patients were statistically more likely to experience superior pain relief and better mood on morphine. Graphs from the paper show that there was clear

individual variation regarding which drug was superior, although there is no indication of how clinically important this was (Figure 4-1).

This trial although one of the earliest which evaluated analgesia in terminal cancer remains one of the largest, establishing the practice of using morphine rather than diamorphine as the standard oral opioid in palliative medicine. This was an important finding as it demonstrated that oral morphine was generally effective despite its poor absorption characteristics and that diamorphine had no particular advantage.

Diamorphine was only available in UK and Belgium at the time (Seymour et al. 2005).

Whether diamorphine is superior to morphine (or vice versa) in some subgroups of patients remains unclear. Since diamorphine is metabolized to morphine it should probably be considered as a 'prodrug' when used in palliative care, i.e. in chronic pain (Twycross and Wilcock, 2001). This pharmacological similarity indicates that there is probably little difference in terms of clinical effectiveness between the two drugs. Of all the 'strong' opioids, i.e. those without a ceiling effect, none has been shown in RCTs conducted in palliative care populations to be clinically superior to morphine in terms of analgesic efficacy (Hanks et al. 2001), even though they do vary in their side effect profiles in clinical trials, e.g. fentanyl is less constipating than morphine, an effect which is well accounted for in terms of the pharmacology of both drugs (Ahmedzai and Brooks, 1997). Clinical experience would suggest, as Saunders highlighted over 40 years ago (1963), that there may be differences in action between opioids in the individual patient and that there is some benefit in using different opioids in different situations. Given the complex physiology for pain which is now apparent (Hansson and Dickenson, 2005) and wide inter-individual variations, whilst RCTs may be useful for testing the efficacy and safety of opioids (and other drugs) in populations, as exemplified by Twycross (1977), they may not present an effective tool in developing a clear evidence base for the differential use of opioids and other analgesics.

In 1996 Saunders wrote that the basic principles of palliative care had not fundamentally changed in 33 years (Saunders, 1996), that is before RCTs had been used in its development. Thus, using opioids in effective and escalating doses as required, analgesia being given regularly rather than on demand and a refutation of

the belief that morphine use led to serious opioid tolerance in the terminally ill, had been largely a result of the observational work of Saunders and others with whom she was in correspondence (Clark, 2002b).

4.2.4 RCT as gold standard for evidence

The RCT was being proposed as the gold standard for evidence for the effectiveness of therapeutic interventions as early as 1962 (Le Fanu, 2000), although the history of the rise of the RCT has not yet been systematically described (personal communication – Dr Martin Edwards, University College London).

Probably the single most prominent and important personal contribution to the place of the RCT as the ‘gold standard’ for medical evidence was that of Professor Archie Cochrane. Cochrane, the head of the MRC epidemiological unit in Cardiff published his important monograph ‘Effectiveness and efficiency’ in 1972 in which he set out the need for RCT evidence, to guide the practice of medicine. Citing the 1948 streptomycin trial, he suggested that this introduced....

‘..to the medical world the techniques of the RCT which added the experimental approach to medical research. Its importance cannot be exaggerated. It opened up a new world of evaluation and control and will, I think, be the key to a rational health service’ p11 (Cochrane, 1972).

Although Cochrane’s monograph was critical of the lack of evidence in the practice of medicine, citing examples of ‘ineffective, unproved and occasionally harmful treatments’ p21 (Thomas, 1997), its message and spirit was widely accepted by the medical establishment.

As well as being personally involved in conducting important RCTs, Cochrane was also instrumental in establishing the systematic review and meta-analysis of RCTs as the preferred method for assessing evidence (Elwood, 2004). Cochrane suggested that systematic reviews of controlled trials should be prepared and maintained for medical therapies, and his vision was later celebrated in the establishment of the Cochrane Centre for Dissemination of Reviews in 1992 and the Cochrane Collaboration, ‘an international network of individuals committed to the preparation, maintenance and dissemination of systematic reviews of research evidence about the effects of health care’ p233 (Chalmers et al. 1997).

4.2.5 Evidence based medicine (EBM)

EBM is a practical tool to enable clinicians to practice medicine based on the best science. Many definitions of EBM exist; the following from the BMJ being the most widely quoted:

‘Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research’ p97 (Sackett et al. 1996).

Whilst Cochrane’s book is seminal for the establishment of RCTs in the assessment of clinical and cost effectiveness of medical interventions, the work of David Sackett is similarly positioned in the rise of EBM. It was Sackett who originally proposed the hierarchy of evidence with systematic reviews of well conducted RCTs at the apex (Sackett, 1986).

Since clinical experience alone leads to bias, RCTs help to define which treatments are effective and which potentially cause harm in a population of patients. Thus, Twycross was able to demonstrate that oral morphine is as effective as diamorphine. Through RCTs other treatments have been shown to be potentially harmful, such as the use of flecainide after myocardial infarction and colloid infusions in critically ill patients (Doust and Del Mar, 2004). However, no robust method exists for using population based evidence from RCTs to decide which treatment to use for an individual patient (Tanenbaum, 1999; Tonelli, 2006; Sweeney, 2001).

4.2.6 The philosophical basis of EBM

Philosophically, EBM assumes a positivist stance (Loughlin, 2003; Pawson and Tilley, 1997). Positivism as a scientific approach has its roots in the 18th and early 19th century (Crotty, 1998) and is born of the concept of ‘positive law,’ i.e. law which exists because legislators have made it, rather than ‘natural law’, which relates to things which are right or wrong by their very nature. ‘Positive science’ is knowledge which is based on observation rather than ‘arrived at speculatively’ p20 (ibid) distinguishing it from metaphysical constructs. The concept of positivism was popularised by Auguste Comte in Paris in the mid 19th century, who advocated a

positivist approach to social improvement. Interestingly, Sackett et al. (1996) also identify that EBM's 'philosophical origins extend back to mid-19th century Paris and earlier' p71, although this probably relates to the physician Pierre Louis who conducted a trial demonstrating the harmful effects of bloodletting (Davidoff, 1999). Positivist scientific method in fact originates earlier with the writings of Frances Bacon 1561-1626, considered to be the first of the British empiricists (Robinson and Mayblin, 2004).

Since proponents of EBM seem to rarely discuss their philosophical assumptions in any way,² the positivist position is implicit in their methods and writing rather than explicit; research thus becomes a process of discovering 'facts' and 'the truth' p1729 (Isbister, 2000). Comments on the philosophy of EBM come mainly from commentators who use a variety of terms which seem to be interchangeably applied, although frequently poorly defined. These include: naïve realism (Mays and Pope, 2000), empiricism (Connelly, 2004; Cohen et al. 2004), logical positivism (Robbins, 1998), post positivism (Tashakkori and Teddlie, 1998; Holmes et al. 2006) and neo-positivism (Scambler, 2002).³ Most of the reflection from within medicine on the positivist nature of EBM comes from those who challenge the approach in some way, suggesting the need to develop a broader view of evidence, e.g. Upshur et al. (2001); Tonelli, (2006); Lipman, (2004); Sweeney, (2001); Kernick, (2006).

The preferred method of inquiry in positivist science is the closed experiment where confounding factors can be excluded (Collier, 1994). Facts and values should be separated with the search for facts being the only permissible scientific activity as values cannot be empirically tested (Popper, 2002); objective truth should be minimally affected by cultural or social factors which should also be relegated to a non-scientific category (Crotty, 1998). Thus within EBM the RCT, with its drive

² If Sackett is referring to Pierre Louis, then he is not describing EBM's philosophical roots, but its methodological roots.

³ This is my understanding of these terms: Naïve realism - because empiricists tend to take knowledge about reality based on observation as being factual and unproblematic (they are naïve about the epistemological-ontological distinction). Logical positivism was probably the most extreme form of positivism and as a philosophy was linked to a group of philosophers in Vienna- "The Vienna Circle" in the early part of the 20th century, who influenced the Oxford philosopher AJ Ayer. They believed in scientific verification which was refuted by Karl Popper. Post positivism is a version of positivism which accepts relativist arguments and is more sceptical about empirical science, although it is associated more with quantitative than qualitative research. Neopositivism refers to the rise in positivism which has occurred both in health (as with EBM) and social science as encouraged by recent UK governments.

towards unbiased objectivity and experimental closure, is raised to the level of the 'gold standard' against which all other evidence must be judged. However, lack of a philosophical, social and cultural awareness of the roots of EBM is problematic. Attention in research tends to be exclusively focused on the internal elements of experimental study in terms of guarding against bias or statistical misuse rather than exploring wider aspects or making a critical examination of the underlying epistemological assumptions inherent in the methodology (Pawson and Tilley, 1997).

4.2.7 RCTs and complex causation

RCTs are experiments in which experimental closure is attempted. They are designed to determine whether in a given population a particular intervention will result in a particular outcome.⁴ Therefore in using RCTs as experiments, three issues need to be considered:

- 1) The *context* in which the trial is being conducted – i.e. the patient group in a clinical trial or the community in which an experimental intervention is taking place e.g. elderly diabetics or a primary care team.
- 2) The *intervention* itself. This may be relatively simple such as a drug, or exceedingly complex, e.g. educational programme.
- 3) The *outcome* which is hoped for. It is important that the outcome should relate to the intervention as directly and clearly as possible and be clinically relevant (or have relevance in relation to it) e.g. HbA1C marker of diabetic control and emergence of complications of diabetes; whilst outcomes of educational programmes could include more confidence in delivery of care, or measures of the quality of care itself.

Simple interventions in relatively simple contexts, e.g. treating tuberculosis with streptomycin follow a simple cause and effect pattern. Treatment A in Context C leads to outcome O thus (A + C >>>> O). In this situation the intervention is clear and is based on a model of biological plausibility; streptomycin has been shown to be

⁴ If I want to discover whether a new drug is effective in lowering blood pressure I select a group of hypertensives, randomise them to either receive the drug or a placebo and measure the effect on blood pressure over time. By having a large enough group I can ensure that on average the characteristics of the group receiving treatment and the group receiving placebo have the same characteristics: age, gender, smoking habits, mean blood pressure at outset etc. If I assiduously follow the well designed protocol to guard against bias and no problems, such as subjects dropping out occur, I assume that the groups are exactly the same, except for the drug intervention. If problems do occur I need to make statistical adjustments to compensate.

active against tubercle bacillus in the laboratory. However problems arise with more complex interventions which do not necessarily follow such a clear line of cause and effect. In these the causal mechanisms may be unclear or may possibly be multiple (Pawson and Tilley, 1997; Byrne, 2004). I will return to the issue of complex causation when I consider critical realism in Section 4.3.3 below.

Opinions differ as to whether simple RCTs are appropriate for complex health service interventions. These need to be rigorously evaluated, preferably before widespread implementation, to avoid the problem of needing to withdraw ineffective services (McDonnell et al. 2006). However, RCTs give no information about the causal factors which might be in operation, which parts are not active or which could even be harmful (Evans, 1995); such insights will only be gained through an observational or qualitative approach.⁵ A framework for RCTs in complex interventions has been suggested by the MRC (Campbell et al. 2000), which involves a phased approach utilizing observational and qualitative studies in early phases in which an attempt to define the active parts of the intervention is made Figure 4-2.

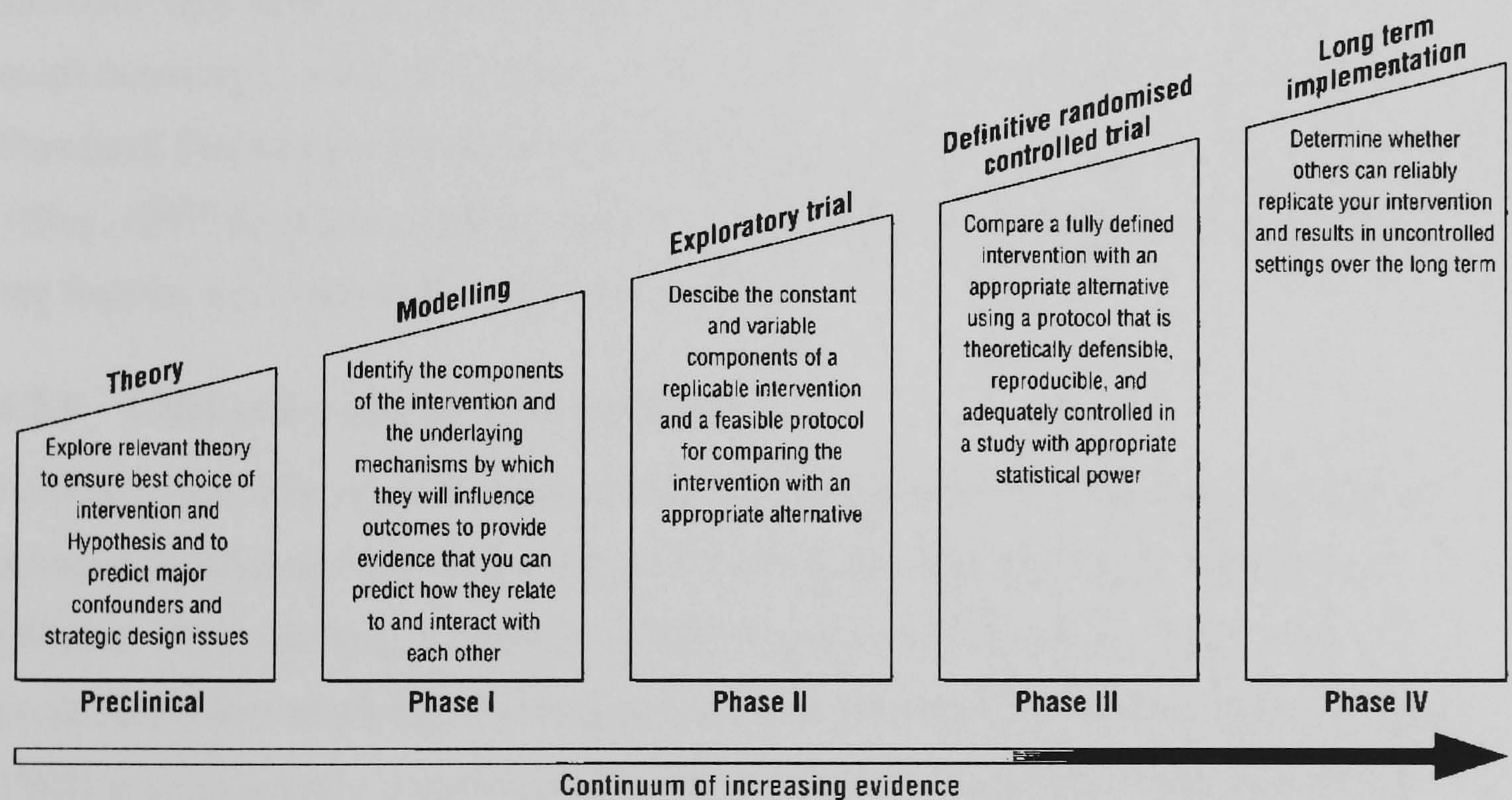


Figure 4-2- MRC Complex Intervention Framework Campbell et al (2000)

⁵ In RCTs evaluating drug treatments, the causal mechanisms are based on biological foundations and these have been investigated in laboratory and animal based studies before being tested by RCTs in humans. The proposed mechanisms for complex interventions are likely to be based on theoretical concepts such as social or psychological theories. Bradford Hill insisted that biological plausibility needed to be established before an intervention was submitted to an RCT, although this has never been adopted as a cardinal rule for conducting RCTs (Ashcroft 2004).

Hawe et al. (2004) take a different view and consider the MRC framework to be flawed. They reason that the intervention may not be understandable through examining its constituent parts and further consider that the essence of the intervention may be lost by attempting to understand it. Their solution is to suggest that rather than trying to understand an intervention in terms of its active components evaluation should concentrate on *function* and *process*. The intervention then delivered at different sites will be standardized according to its function rather than to the elements which make it up. So for instance a workshop for general practitioners (function) will be considered the mechanism for change and holding the workshop will be the process. The actual mechanisms in the workshop will be left unexplored, i.e. considered as a black box.⁶

It is a little difficult to see quite what is being investigated in this situation and what benefit a RCT would give in evaluating such an intervention. However, I do agree that there are problems with the MRC framework (see Section 4.2.8 below) and it may be preferable in highly complex interventions to utilize an alternative method such as a case study approach (Walshe et al. 2004), in which comparisons can be made between a variety of contexts, as we have done in our evaluation of the Gold Standards Framework (Munday et al. 2007a), or a realistic evaluation (Pawson and Tilley, 1997) based on a critical realist – critical methodological pluralist approach - see Section 4.3.7 below (Pawson et al. 2005).

4.2.8 EBM and palliative care research

Palliative care, like other branches of medicine and health care, has been expected to develop its evidence base according to the hierarchy stipulated by the EBM project (Wiffen, 1998; McQuay and Moore, 1994; Bennett and Ahmedzai, 2000). EBM proponents have explicitly challenged it to do so (McQuay and Moore, 1994; Wiffen, 1998) and the science committee of the Association for Palliative Medicine (APM) in the UK whilst noting procedural problem with RCTs have explicitly adopted EBM's strict hierarchical grading of evidence (Bennett and Ahmedzai, 2000). It is normally implicitly assumed in the palliative care literature that palliative care should follow the rules of EBM, e.g. Lunder et al. (2004) and that the task is one of

⁶ I agree that the functioning of a complex intervention may not be reducible to its individual parts; however, I do not agree that the mechanism is completely unknowable. Otherwise science apart from investigating simple systems would be ineffective (see Section 4.3.3).

generating evidence rather than offering a critical examination of the foundations of EBM (Ling et al. 1995). Higginson (1999b) comments on the methodological problems of conducting RCTs in palliative care and expresses concern that this is a barrier to palliative care generating a robust evidence base.

Some commentators from within palliative care, have explored issues surrounding the role of RCTs in the discipline amongst which are Corner's (1996) deliberations as discussed in the introduction to this chapter (Section 4.1). Robbins (1998) takes a more epistemological approach, commenting that experimental evidence has been criticized for 'oversimplification, artificiality and control', and observes that 'advocates of qualitative methods, which can better cope with diversity and multiple perspectives, have failed to deal with the issue of validity in a way that is wholly convincing to planners and decision makers' p12 (ibid).

Aoun and Kristjanson (2005), whilst accepting that RCTs are the gold standard and proposing that palliative care research 'meets the criterion whenever possible' p465 are concerned with the exclusion of the most disadvantaged groups from RCTs because of practical and ethical difficulties with the methodology. They suggest addressing this with a model of evidence grading and guideline development which takes context, meanings and ethical considerations into account. Only Soloman, (2003) suggests that 'the RCT design should not necessarily be seen as the gold standard in end of life care research' p284. She explores in some depth various underlying philosophical assumptions associated with quantitative research and discusses methodological issues around RCTs: for example, lack of utility for exploring causal mechanisms and failing to give insights into why RCTs fail as most do (Rinck et al. 1997); her reasons for questioning their gold standard status largely relate to cost and inherent delays in obtaining results. Instead she advocates continuous quality improvement (CQI) as an empowering method for programme development within palliative care (Lynn et al. 2002), drawing heavily on behavioural and organisational theory as levers for change. She seems therefore to side step the issue of how a general evidence base can be developed, but rather adopts a local service development approach.

RCTs are difficult to undertake in palliative care. In Section 4.2.3 I described Twycross' morphine-diamorphine trial and briefly highlighted some of the

difficulties with drug RCTs, particularly related to heterogeneous unstable patient populations and lack of clarity concerning specific pharmacological effects.

Few RCTs of non-drug palliative interventions have been attempted (Currow et al. 2006) although three which have been relate to provisions of clinical services in the community. McWhinney et al. (1994) in Canada attempted to test the effectiveness of a palliative home care team, however difficulties in recruitment, attrition – mainly due to death and low compliance in completing outcome questionnaires led the trial to fail.

A hospital at home service provided for terminally ill patients in Cambridge, failed to show any statistically significant increase in home deaths when analysed on an intension to treat basis. Like McWhinney, the authors report that problems with recruitment and high levels of attrition between allocation and taking up the service were likely to have contributed to the failure to reach significance (Grande et al. 1999). However several secondary end points showed significance: fewer GP visits were made in the penultimate week before death, GPs reported a reduction in anxiety and depression amongst carers, DNs reported better night care and relatives reported less nausea and vomiting in the treatment group (Grande et al. 1999; Grande et al. 2000).

In another study, a co-ordinator of home care was established for patients in one area of South London and outcomes were compared with a matched control area. Only minor differences were found between the intervention and control groups (Addington-Hall et al. 1992), except fewer hospital days and nurse visits in the intervention group were estimated to have led to cost savings of between 1:4 and 1:8 (Raftery et al. 1996).

The major problem with interpreting the results from these studies is that little contextual detail is given regarding the areas in which they were conducted, so that knowing how the intervention might translate into other areas is problematic. In addition since no qualitative studies conducted alongside the RCT were reported, little insight is given into the operation of the services or the less quantifiable outcomes, e.g. the relationships developed between the HCPs involved in the intervention, the clients and other HCPs.

Grande and Todd (2000), in a discussion paper in which they explore some of the reasons for their study failing, acknowledge the utility of observational and qualitative studies in evaluating such interventions and indeed recommend that any further such programmes should be undertaken using the MRC complex interventions framework. Interestingly, this paper attracted a response from Saunders and Twycross, anxious to encourage palliative care researchers not to abandon using RCTs – citing Twycross’ original morphine-diamorphine RCT in support (Saunders and Twycross, 2000).

Using the complex intervention framework as it is presently configured will lead to very complex studies, which will take a long time to complete, given the phased approach (Figure 4-2) and will be expensive to perform. Whether the evaluation of complex interventions using the MRC framework is feasible in palliative care remains to be seen since none have been completed so far. However, the MRC framework is under review and a recent publication has indicated a more flexible and integrated approach, with more emphasis on the first three phases and the explicit use of theory to interpret empirical data (Campbell et al. 2007). These developments may be moving the framework towards a more critical realist position as described in Section 4.3.3 below. However the principle still remains, if RCTs are likely to fail, they are arguably unethical in terms of the risks to patients and wasted resources; therefore they should not be attempted, particularly if more appropriate methods for research exist.

4.2.9 Interpreting evidence in palliative care

One final area of concern which will be addressed is the interpretation of RCTs in palliative care.

Such is the strength of the discourse to provide evidence for practice on the basis of RCTs that judgement can be subtly affected. It is my experience that if RCT evidence is claimed for an intervention, little scrutiny of the true results often ensues. Hard pressed clinicians can apply such evidence in a largely unexamined way which leads to a poor result (no effect or worse) for the patient (Evans, 1995; Dewhurst, 2004). Sweeney (2001) suggests that EBM evidence can lead to disingenuousness in the consultation, with the patient wanting certainty and the doctor offering it because

they have ‘evidence.’⁷ Thus there is a danger that EBM can produce a gloss of certainty in an inherently uncertain world (Fox, 2002; Griffiths et al. 2005).

	Grading of reliability and quality of evidence supporting recommendations (NICE 2004) p28
A	Evidence derived from randomised controlled trials (RCTs) or systematic reviews of randomised trials
B	Evidence from non-randomised controlled trials or observational studies.
C	Professional consensus

Table 4-1 - NICE grades of evidence

Reviews of evidence may also present results in a potentially biased way. The NICE guidance on supportive and palliative care (NICE, 2004), using grades of evidence as in Table 4-1, reports the co-ordinator (Addington-Hall et al. 1992) and hospital at home (Grande et al. 1999) studies thus:

‘Nurse coordinators appear to improve co-ordination between in-patient and home care teams, reducing the number of days spent by patients in hospital and the number of home visits [A]’ p132.⁸

And

‘An RCT of a hospital-at-home service for terminally ill patients found carers had greater satisfaction with the care provided, although there was no increased likelihood of patients remaining at home in the last two weeks [A]’ p165.

These conclusions are superficial and no attempt is made in the text to caution the reader that these could be highly context specific. In addition no references are given for these studies in the guidance for the reader to scrutinise the evidence themselves. Presentation of results in a simple format does represent a challenge, however encouraging a view that assessing evidence can be simply achieved through a

⁷ Sweeney cites the Secretary of State for Health who advocated ‘delivering the right evidence to the right person at the right time’, suggesting that this demonstrates a common misunderstanding of evidence.

⁸ In both of these examples – ‘A’ represents grade A evidence.

hierarchy largely based on statistical considerations and a dubiously reductionist approach to evaluation is open to abuse (even if unintended).⁹

Similarly there is evidence of misuse of EBM in supporting clinical practice in palliative care. Good and Stafford (2001) report on a survey in their inpatient unit claiming that 81% of their interventions were 'evidence based' ('evidence from randomized controlled trials 48%, evidence from other trials 27%, convincing non-experimental evidence 6%' p493). It is unclear in their paper how they assessed whether the evidence quoted for the intervention applied to the clinical condition faced, but there seem to be some problems. For instance, the reference given in support of giving the drug omeprazole to their patient with haematemesis, reports the effectiveness of this drug in bleeding peptic ulcers. It is unclear from their paper if the patient had a bleeding ulcer and it is unlikely that the study referred to as evidence included patients with terminal cancer. Similarly, amitriptyline was given for neuropathic pain, but the reference is for diabetic neuropathy.¹⁰ This paper was presented at a recent national update forum I attended, where it was suggested that it illustrates that inpatient palliative care is evidence based. I would suggest that such a conclusion is contentious. I am not arguing against these treatments, merely illustrating the inherent danger of elevating one research method and not applying rigorous critical appraisal to it.

The first ethical principle of clinical practice, to do no harm, is at the heart of EBM (Saarni and Gylling, 2004). It was one of the principles which led Cochrane to challenge medicine to provide evidence for its interventions. Whilst the need for a scientific evidence base in clinical practice is incontrovertible, the question remains as to whether the current underlying principles and practice of EBM are adequate (Loughlin, 2003). I would argue that for palliative care they are not, leading to philosophical and practical problems.

⁹ In addition that results can be misrepresented was illustrated in recent months when a government minister claimed that a study of DN training in palliative care had demonstrated improved care for dying patients in the community.

<http://www.gnn.gov.uk/content/detail.asp?ReleaseID=217261&NewsAreaID=2&NavigatedFromSearch=True> (Accessed 16-03-07). It had shown increasing confidence in DNs following training, but no measures of care showed any change

¹⁰ Palliative care units rarely see patients with diabetic neuropathy in comparison to cancer related neuropathy.

In Part 1 of this chapter I have drawn heavily on drug related research because this is necessary to explore the history of RCTs, however in the second half of this chapter, I will mainly discuss examples of social and applied health service research, since this is the focus of the thesis.

4.3 Part 2 - Critical realism: a philosophical approach

4.3.1 Introduction

As discussed above, EBM is currently based on an empiricist/positivist philosophical position, although this is largely unexamined within medicine so that the assumptions and implications of this are rarely appreciated (Cohen et al. 2004; Ashcroft, 2004). This is reflected in the poverty of teaching on these issues even at higher levels in disciplines such as epidemiology in which clarity in this area should be fundamental (Pearce, 2000).

The positivist position has been criticised as assuming a simple relationship between reality (ontology) and our knowledge of it (epistemology), effectively reducing ontology to epistemology - dubbed the 'epistemological fallacy' (Collier, 1994), i.e. what is real about the world equates to our description of it through our experience. Empiricist concepts of reality also fail to recognise the socially constructed nature of knowledge, hence the insistence on needing 'facts' to enable 'a hypothesis to be tested' so that 'the truth' can be attained p1729 (Isbister, 2000). Conversely the post-modern world view suggests that the social construction of all knowledge makes it meaningless to talk about external reality or truth, since knowledge depends on perspective. Scientific explanation becomes one of several discourses for understanding the world and this should in no way be privileged (Benton and Craib, 2001). Interestingly this can also be labelled as an epistemological fallacy, because it similarly assumes that 'what is' (i.e. reality), must be the same as what is known; however (according to postmodern theory) since what is known varies according to perspective, reality must be relative (Collier, 1994).¹¹

¹¹ This is empiricism and postmodernism in its "pure form". As with all ideal types, in practice many positions are taken and a spectrum is formed between these two types (Pawson and Tilley 1997).

4.3.2 Ontological realism – epistemological relativism

Critical realism, which emerged as a philosophy of science (and particularly social science) in the late 1970s onward presents an alternative to the empiricist and the relativist view (Benton and Craib, 2001). Critical realists purposefully separate out epistemology and ontology, insisting that epistemology is relative, i.e. knowledge is based on perspectives, is socially and culturally conditioned and our experiences are interpreted on the basis of this; whereas there is a reality which exists independent of our knowledge and our experiences of it¹² (Collier, 1994). From this two ‘realms’ emerge – the ‘transitive’ representing ‘our knowledge about the world’ including scientific theories and the ‘intransitive’ representing ‘the world which is the object of that knowledge’ p2 (Carter and New, 2004).

Thus for the critical realist, knowledge is ‘fallibilistic’ p50 (Collier, 1994); what we know about the world is determined by our experience and the theories which we develop based on that experience. The purpose of science is to explore the world empirically so that on the basis of our observations, the theories we are able to generate from these observations and pre-existing ‘knowledge’ we can come to a better understanding of the world (Danermark et al. 2002). As scientific knowledge progresses, we aim to generate better theoretical concepts which explain reality, however these will always be transitive and thus fallible (Collier, 1994).

However, we come to understand the world, not by trying to merely discover regularities in our empirical observations (as in the empiricist method) but by exploring generative mechanisms, i.e. underlying causal factors (Pawson and Tilley, 1997). The critical realist insists that the search for causal mechanisms necessitates theoretical abstraction from the empirical to the real (Danermark et al. 2002), which entails conceptualizing the transitive realm as having three levels: the empirical, the actual and the real (Benton and Craib, 2001). The empirical is the level of our observations or what we consciously record; however, this is only a subsection of the ‘actual,’ i.e. what is actually there. For instance, when I interview a patient about the experience of being admitted to hospital, I will only uncover a fraction of what

¹² Most modern empiricists believe in reality external to our experience. Bishop Berkley the 18th century empiricist did not believe this taking a soliptical position. For realists in general (including empiricists) the existence of external reality is a reasonable assumption although it cannot be proved philosophically.

‘actually’ happened. Also, to understand the cause of events we need to go deeper, to ‘the real’. This will require some sort of abstraction: for instance, ‘A’ was admitted to hospital by ambulance (the empirical); however, the ambulance was called by ‘A’s daughter, who found her collapsed and could not get hold of the GP (the actual). ‘A’ was admitted by ambulance because of lack of availability of the GP (the real).

Clearly this is a very simple example and the level of abstraction is very low and thus the causal mechanism is likely to be incomplete and cannot be judged accurate without other supporting data about why she was not able to get hold of the GP. However, it can be seen that abstraction from the empirical and actual to the real is the normal process by which humans explore causation. This scenario could be recounted by the neighbour over the garden fence, or by a researcher undertaking a survey in an A/E department. What the researcher will want to do however is collect as much reliable data as possible, linking findings with data from other patients and key informants, contextualizing what they know about local primary and community care and generate theoretical ideas from the data, critically linking these with relevant pre-existing theoretical concepts. These are obviously not methods which are exclusive to critical realism, however the theoretical concept of empirical, actual and real, does make this process of causal abstraction *explicit* and in doing this opens up the possibility of exploring causal mechanisms more fully.

4.3.3 Complex causation

Critical realism insists that the proper function of science is to explore causation by searching for generative mechanisms.¹³ However, it recognises that causation is complex and rejects the idea of constant conjunction of events as the basis for inferring causality, the assumption which is the basis of empiricist causal explanations. In addition critical realists highlight the fact that symmetrical explanation and prediction only occur in simple closed systems or systems which can effectively be closed (Pawson and Tilley, 1997). Such symmetry of cause and effect is also dependant on interactions which are linear (Byrne, 1998), as in classical Newtonian physics. Thus when a golf ball is hit it will travel in a certain direction and the cause for its particular trajectory can be explained through video analysis of

¹³ In critical realism, the term generative mechanism is normally used for causal mechanism in a complex system.

the golfer's swing. The coach can say to the golfer "if you hit the ball like this, it will end up going there," i.e. explanation and prediction are symmetrical. However, in an open system, such prediction is not possible. In golf, a sudden gust of wind can throw a ball off its predicted trajectory. The system is not closed so the trajectory of the ball is affected by the contingent action of the wind.

The more open the system, the more the outcome is contingent on a multiplicity of causal factors. Causal factors in open systems need to be looked upon in terms of 'powers' and 'tendencies' (Collier, 1994). For example, giving morphine to a patient with abdominal pain tends to cause pain relief. Morphine has the power to relieve pain, and this power is realised given other contingent conditions, i.e. the patient takes the morphine, it is absorbed, the type of pain is sensitive to morphine and there is no 'wind up'¹⁴ which tends to block its action.

Causal tendencies, often in combination, can be seen to produce patterns in complex systems which are relatively enduring partial regularities termed 'demi-regs' (Lawson, 1998). In health care the 'inverse care law,' i.e. patients' ability to receive the benefits of health care initiatives particularly in a free market economy is inversely proportion to their social class status (Hart, 1971), could be seen as an example of a demi-reg as could social class in terms of wider health inequality (Scambler, 2002). Underlying these demi-regs will be causal mechanisms which interact in a complex manner, the nature of which will be contextually specific. Collapsing demi-regs into an explanatory variable, e.g. social class, will miss the depth of explanation which may be possible with deeper exploratory research (Byrne, 2004). Such quantitative variables in social systems should not be considered as 'reality' but as 'traces of reality' (Byrne, 2002). Such variables, often selected for ease of measurement as much as explanatory power are often a good starting point for research, but not a satisfactory conclusion (Carter and New, 2004).

Social systems are never closed, although it is possible to approximate to a closed system by considering a relatively circumscribed one, e.g. organisation or family; Danermark et al. (2002) term this a 'pseudo-closed system' p186. Experimentation searching for cause and effect requires systems to be closed (or virtually closed).

¹⁴ Wind up occurs in the dorsal horn of the spinal cord, when activated local inhibitory pathways which develop over time block the effects of analgesics so that the pain sensation is transmitted despite the analgesic.

This would seem to limit the utility of the MRC complex interventions evaluation framework to systems which can be virtually closed or ‘pseudo-closed’. Thus the investigation of a stroke unit or cognitive behavioural therapy (CBT) in a relatively homogeneous group of patients is possibly feasible, although it is the qualitative and observational research which will be more illuminating in terms of causal mechanisms. However, use of the framework in situations in which the system is impossible to close or closure would alter the system fundamentally render the experiment meaningless. Therefore evaluating a highly complex intervention in an extremely complex context (e.g. the Gold Standards Framework for Palliative Care) would seem not feasible. There may be no clear cut off point for deciding whether an RCT is appropriate, however I propose that a useful illustrative model can be constructed as in Figure 4-3.

Diagrammatic representation of levels of complexity in health services evaluative research					
HIGH COMPLEXITY					
INTERVENTION	Highly complex intervention		Training programme in EBM for medical students in same year at same medical school	Stroke Unit (MRC COMPLEX INTERVENTION)	GSF in palliative care RCT not feasible as a methodology for evaluation
	Intermediate intervention	Psychological “lab” trials	Utility of Pilates technique in injury prevention with rugby team	Physio for back pain	Palliative Care Breathlessness clinic (MRC COMPLEX INTERVENTION)
	Simple intervention	Animal laboratory drug testing	Phase 1 clinical trial in volunteers	Clinical drug trials	Clinical trials in palliative care Simple intervention with complex sample - ? suitable for RCT
		Lab control - animal	Volunteers – homogeneous group	Relatively homogeneous clinical sample or “Simple” organisation	Heterogeneous clinical sample or complex organisation
LOW COMPLEXITY			HIGH COMPLEXITY		
CONTEXT – Clinical or organisational					

Figure 4-3 - Complexity in Evaluation Research

Thus in Figure 4-3 – experimental conditions (a closed system) are more achievable in the bottom left hand corner of the diagram and become increasingly problematic towards the top right, since both the intervention and the context become more complex. At the top right closure is either impossible or attempting it renders insights meaningless as closure radically alters the system. In other words with increasing complexity, attempting closure moves a system further from reality. Also, controlling for other variables has the effect of averaging out ‘noise’ which may contain

important clues to explanatory mechanisms. Guba and Lincoln (1989) put it clearly (cited in Pawson and Tilley, (1997)):

‘Experimentation tries to minimize all the difference between experimental and control groups and thus “effectively strips away the context and yields results that are valid only in other contextless situations”” p22.

Since in real complex situations cause and effect does not occur with either the regularity of constant conjunction or the symmetry of explanation and prediction, it is more useful to see outcomes as ‘emerging’ from complex causal mechanisms. In a complex system, objects will have causal powers and tendencies, but whether these are activated into mechanisms which effect the outcome or whether if activated these mechanisms are obtunded will depend on their interaction with other contingent objects, with their powers, tendencies and mechanisms within the system (Collier, 1994). Thus the object of realist research is to investigate for various emergent outcomes; which mechanisms have been activated in which contexts (Pawson and Tilley, 1997).

4.3.4 Stratified reality

Stratification of Reality (Benton and Craib 2002)
Social sciences
Psychology
Physiology/ anatomy
Organic chemistry/ biological chemistry
Physical chemistry
Physics

Box 4-1 - Stratification of Reality

Another fundamental aspect of critical realism is the understanding of reality as being stratified (Box 4-1) with each layer of reality needing to be investigated using its own appropriate methods.

Objects in each level emerge from mechanisms at a lower level; however they themselves have causal properties which cannot be reduced to those of the lower level.¹⁵

For objects at higher levels particularly the situation is more complex. For instance the mechanisms controlling the emergence of the reproductive cycle of an animal might depend on an interaction of hormone levels, day length, temperature, presence of a mate etc, i.e. from different levels. Feedback mechanisms may cause objects at a higher level to affect the mechanisms of those at a lower level, e.g. concentration of emergent complex molecules affecting the reaction of constituent simpler molecules.

The relative position of social and psychological layers is more problematic to determine. Whilst people make up society and the psychological domain represents that part of a person operant in volition and action, it would seem logical that the social should emerge out of the psychological. However, psychological issues are strongly influenced by social factors and therefore emerge partly from the affect of these. Therefore it may be more accurate to place these two domains at the same, although distinct level (Collier, 1994). In addition the social layer in itself can be seen as being stratified, a feature which has been explored in detail by Layder and formalised in his theory of social domains (Layder, 1997; Layder, 2006).¹⁶ In addition to emergence at higher levels being more complex, further complexity for the social layer is added through individuals being reflective and able to modify their own actions and the effect those actions will have on other individuals and objects in other layers.¹⁷ Reasons in themselves can be seen as causal as I have argued in Chapter-3 (Section 3.5.2 page 97) regarding reason for admissions. Carter and New (2004) make the point clearly:

¹⁵ Thus the properties of water, cannot be reduced to hydrogen and oxygen or the activity of the brain cannot be reduced to that of individual neurones.

¹⁶ The two most obvious levels of social reality are structure and agency. Broadly speaking social theorists form four groups: Structuralists and functionalists consider the primary of structure as the cause for social emergence, whilst phenomenologists and interactionists view human agency as having causal primacy. The third group, defined by Archer and drawn on by Layder, advocate “central conflation” p264 (Layder, 2006) – those who reduce the duality into a single issue – (including Giddens, Foucault, Bordieu). The fourth group, the ‘dualists’ develop various theories of interaction between agency and structure e.g. Archer, Baskhar, Layder (Layder, 2006). Space does not allow a detailed exploration of the specific issues which arise from the debate surrounding structure and agency, neither is it central to this thesis, although it should be noted that not all critical realists hold a dualist view (Baskhar and Harre, 2001).

¹⁷ e.g. performance of experiments on objects in lower levels.

‘Humans are structured beings, in whom reasons, beliefs and intentions bring about actions, and.....to “bring about” is to cause’ p3.

Of fundamental importance to the critical realist approach to health service research is the appreciation of the ontological depth of the social world (Pawson et al. 2005). Empiricist understanding sees social reality as relatively ‘flat’ since it is reduced to what can be perceived through our observations (Danermark et al. 2002). This is problematic, especially in a complex discipline such as palliative care, as it can lead to a narrow approach, where complexity is not appreciated and important causal factors are ignored.

4.3.5 ‘Flat social ontology’ in palliative care research

As an example to illustrate this limited ontological position, I will discuss a recent systematic review published in the BMJ entitled ‘Factors influencing death at home in terminally ill patients with cancer’ which developed a model for considering issues relating to place of death (Gomes and Higginson, 2006). Using an extensive search process the authors identified and reviewed quantitative studies presenting factors associated with place of death, grading studies as to their quality and assessing the strength of statistical evidence emerging. Seventeen factors associated with home death with the ‘highest strength evidence’ p515 were identified and grouped under three categories, forming the basis for an explanatory model:

- 1) the illness (e.g. tumour type, length of illness, level of functioning)
- 2) individual factors (e.g. good social conditions, ethnic group, preference for place of death)
- 3) environmental factors (e.g. health care received, social support, and regional and national trends in place of death).

Many of these factors are formed from a combination of diverse variables. For example, ‘good social conditions’ – ‘included living in areas of low deprivation, medium or high social class, higher level of education or increased years of study, and medium or high income’ p158, arguably a good example of ‘traces of reality’ as discussed above (Section 4.3.3). However, they combine studies from different health contexts in different countries throughout the world raising questions regarding the validity of this construct.

Possible reasons underlying the associations which arose are discussed using the literature to provide possible causal explanations. However, they explore these issues using a low level of abstraction, which results in their insights into causal mechanisms for enabling home death being limited largely to the empirical level.

As an example, whilst they highlight the strong predictive effect of preference for home death, they did not examine issues which challenge the concept of preference, which has been demonstrated as fluid and rarely stated in categorical terms and contingent on numerous social and personal factors (Thomas et al. 2004), with preferences possibly changing in the course of the illness (Hinton, 1994a; Townsend et al. 1990). Nor did they examine structural issues related to death in a society where older people tend to be marginalised and where their values may be at variance with dominant views, whilst their voices are unheard (Gott et al. 2004). In addition, issues regarding social attitudes to death in the community leading to the ‘sequestration of the unbounded body’ (Lawton, 1998) are not considered nor is the conflict between the dominant socio-political discourse extolling choice at the end of life and the stark realities of death where choice is frequently illusory (Drought and Koenig, 2002; Munday et al 2007c).

Exploring the issues in terms of ‘depth realist’ social theory is not the only valid approach to this topic, but the authors of the review give little indication that they consider it necessary to explore complex socio-structural issues to gain a more complete understanding of place of death.¹⁸ Rather they take an instrumental view and suggest that their model in itself is sufficient for health service planning, critiquing current policy frameworks from this perspective.

In the review there is also a subtle shift from discussion of factors ‘associated with’ home death to presuming that these factors are in themselves causal.

‘In this systematic review we found strong evidence for the complicated network of factors that affect the place where patients with cancer die....’

and

‘There is high quality and consistent evidence for the effect of 17 factors on place of death’ p518 (ibid).

¹⁸ Although they do mention the need to explore cultural issues with regard to ethnic minorities.

The authors do indicate the difficulty with assigning causation, but this is in terms of the quality of the data, rather than deeper epistemological considerations, revealing their empiricist assumptions, thus:

‘Our review has several limitations: the completeness of search, heterogeneity between studies, criteria for grading the strength of evidence, classification of place of death, the state of knowledge on the topic, and the reliance on retrospective and cross sectional data in many studies. Thus, we could show associations which do not necessarily indicate directionality or cause’ p518 (ibid).

Danermark et al. (2002) make a general point regarding such a scientific approach:

‘When a quantitative approach discloses an empirical regularity, this is neither a necessary nor a sufficient condition for explaining a phenomenon’ p154.

Gomes and Higginson present a well conducted review of quantitative studies which helpfully clarifies an area in which many individual studies had been performed; however, lack of depth in the conclusions and suggestions for practice that fail to capture the complexity of the issue are problematic. Replacing flat empiricist ontology with a depth realist one such as provided by Layder’s domain theory, I would argue, is key to gaining a deeper and broader understanding of social phenomena and also for avoiding leaps from association to causation.

4.3.6 Theory of social domains

Rather than approaching social ontology by relying on the broad categories of structure and agency, Layder suggests a model of four domains (Box 4-2):

- psychobiography,
- situated activity,
- social settings and
- contextual resources.

Psychobiography – defines the person, their psychological make up and their history - the things which have shaped it, i.e. past experiences.

Situated activity – the domain in which social interaction takes place and involves the activity between individuals either alone or within social groups, e.g. discussions in a coffee-bar, on a bus, in a scientific congress etc.

Social settings – interaction occurs within a social setting. Differing social settings will influence the type of interaction between agents which are determined by social conventions, e.g. the appropriate interaction in a doctor's surgery, in a patient's home or in a football crowd.

Contextual resources – this denotes the social structures which are important factors in social activity and relations. Can be seen in things like banking, the internet, newspapers, but also authority structures, e.g. General Medical Council, professional groupings, NHS procedures.

Box 4-2 Layder's theory of social domains

These domains have parallels with the 'life-world' and 'system-world' suggested by Habermas (Layder, 1997; Benton and Craib, 2001; Carter and New, 2004; Layder, 2006), with psychobiography and situated activity closely related to life-world and social settings and contextual resources to system-world. This is not strictly another way of expressing agency and structure, although structural elements predominate in the system-world whilst agentic ones do so in the life-world. Layder (2006) argues that the social world is much more textured than the division of structure and agency might suggest, and suggests that 'we must understand agency-structure links as embedded within an ontologically differentiated latticework of social reality' p298.

The domain of situated activity is where social interaction takes place. The nature and effects of this interaction emerge partly out of the psychobiography of the social actors and partly from the social setting, which affects the general rules of engagement. For instance, in a classroom (social setting), certain behaviour is expected by the students and the teacher. However, that interaction (situated activity) will be affected by the psychobiography of the individuals involved. In each social setting 'contextual resources' are accessed which both facilitate and constrain social interaction. So in the classroom: school rules, government education policy, legal

requirements regarding the conduct of social relations, societal norms and expectations etc, both enable and restrict education and allowable social interaction.

Thus each domain affects all others in a complex interacting fashion, but each has ontological distinction. 'Each domain although deeply interwoven and interdependent with the others, also has its own distinct characteristics and a certain measure of independence from the others' p4 (Layder, 1997), with the effect that the 'relationship between them produces a "dialectic of separateness and relatedness"' p27 (ibid).

Domain theory adopts what Layder terms 'a moderate form of objectivism' p21 (ibid). By this he claims to avoid the criticism made of social ontology which reifies social objects (institutions and practices), such as happens with forms of functionalism and structuralism, which tend to subsume the role of the individual.

Domain theory is thus:

'Based on the assumption that objective and subjective aspects of social life are interdependent and mutually influential in shaping social practices. So in this sense, objectivism simply points to an objective realm as an important constitutive feature of social life. It does not suggest that it is the most important or that everything else can be explained in terms of this realm alone' p21 (ibid).

Thus whilst social structures are reproduced through social interaction, they are in themselves relatively enduring and cannot be reduced to the activity of actors themselves. However over time the situated activity of actors and will modify the social structures, as can be seen in the example of language. This is relatively enduring and is reproduced in conversation and in writing, however over time new forms emerge and old ones disappear (Carter and Sealey, 2004). If language was not a reproduced structure and relatively enduring, conversation would be impossible as no-one could be understood.

'Properties emergent over time' is an important feature in domain theory (Layder, 2006). Domains describe the vertical aspects of social ontology, i.e. they give the social world depth. Social analysis utilizing domains results in 'freezing the frame' or 'artificially examining action from the point of view of a fixed point in time' p24 (Layder, 1997), i.e. it is an analytical device used to emphasise the ontological depth of the social world. However 'social processes are never static, they constantly move

through space and time. In this sense the layers or domains are stretched out along a horizontal axis, depicting the ever-flowing nature of social processes and human activities' p274 (Layder, 2006). The timescales of change in the different domains vary greatly (Layder, 1993). Thus the psychobiography of an individual changes relatively slowly through their lifetime, whilst the timescale involved in situated activity may be short, or even fleeting (e.g. interactions in a bus queue), although they will be much longer in terms of relationships such as marriage. Timescales of social settings or contextual resources tend to be on a higher order of magnitude in terms of time. Institutions, such as those of state, may evolve very slowly as may social attitudes towards gender or race.¹⁹

Maintaining the continuity in the social world over time is dependant on 'relations of power' p157 (Layder, 1997). Power, Layder suggests, drawing on Foucault, 'is ubiquitous: its influence is everywhere in society from the level of state to the finest capillaries of the routines of every day life' p13 (Layder, 1997). Whilst agreeing with Foucault that power is linked with knowledge and discourse, Layder also stresses that power operates at the structural and the psychobiographical level, so that forms of structural domination do exert power over those subordinated to it, however, power is also a productive force used by individuals to achieve their aims and ends. Thus power is 'multiform' p15 in its nature and:

'an integral part of the structural (or systemic) parameters of society at the same time as it can be considered a discursive practice, an aspect of human agency and an element in the psychological make up of individuals.....Such a multifaceted conception of power is needed in order to adequately represent its ever-present and ubiquitous nature' p15 (ibid).

I will use Layder's concepts of power as a multiform force when exploring the issues around emergency admission of patients into hospital beds in Chapter-5 (Section 5.5.4.1 page 224).

Emotion is also regarded by Layder as a ubiquitous force which accompanies power at every level of social life as a 'behind the scenes co-ordinator' p16 (ibid), coursing through all of the domains. He suggests that emotion is relatively ignored in social

¹⁹ I discuss time in the emergence of social structures in detail in the final chapter (Section 7.3 page 288).

theory because it is repressed and hidden from view, but unless its presence and its effects are acknowledged and explored, important explanatory aspects of the social world are lost. In each social setting there will be rules governing the display of emotion and Layder provides a useful analytical framework which I will explore in Chapter-6 (Section 6.3.1 page 241), when I consider the theory of emotional labour (Hochschild, 2003) and issues of gender as manifest in 'caring' and its relation to the work of Health Care Assistants (HCAs) in palliative care.

Having given this brief overview of domain theory I would suggest that it provides a useful lens for both examining and researching palliative care practice. Layder claims that unlike other high level social theories (i.e. it is a meta-theory of social ontology rather than a mid-range theory, e.g. theory of emotional labour), it spans the whole social world. Thus it highlights the importance of social structural objects, but also gives equal weight to the psychological and biographical issues of individual actors. These issues need to be taken into account to obtain a full appreciation of palliative care practice and the world inhabited by patients needing palliative care services. The discipline rightly centres psychological and social factors, including relational and biographical aspects of patients' lives.

4.3.7 Critical methodological pluralism: – The 'research paradigm' for palliative care?

So far I have not discussed the role of qualitative research methodologies in evidence generation in any detail, although I have alluded to their usefulness in generating insights into causal mechanisms. This lack of examination is primarily because qualitative research is considered rather peripheral to generating an evidence base within EBM.

Whilst qualitative research offers extremely useful tools for exploring complex social phenomena, like quantitative methods it needs to be based on a robust understanding of epistemological and ontological principles. A phenomenological approach which considers only the activity and meanings of individuals and does not consider the effect of social structures has an overly narrow social ontology (Layder, 1997). Thus Danermark et al. (2002) point out that grounded theory, whilst often recommended as an alternative method to positivist research, can be problematic if it employs an empiricist ontology, engaging at the level of data and a fairly low level of abstraction

only. Coding and labelling of raw data is undertaken to enable theory to emerge, with some researchers considering that established theory is an impediment rather than a resource. However, such an approach inhibits a depth realist understanding. Thus whilst theoretical insights relating to the meanings and interpretations which the subject applies to social situations will emerge, this also produces a rather flat social ontology – albeit of a different sort to quantitative research, i.e. insights into meanings for individuals will replace associations of variables.

As I discussed in the introduction to this chapter (Section 4.1), Corner (1996) called for the development of a ‘multi-method, multi-perspective, multi-subject and multi-disciplinary’ p208 research paradigm for palliative care. What is clear from her review and others, e.g. George (2002), is that research in palliative care uses an eclectic mixture of methods. Field et al. (2001) discuss this at length taking up the position that quantitative and qualitative research come from radically different approaches to reality. Giving much the same description as I have given regarding the positivist paradigm, they give a social constructivist account of the qualitative paradigm:

‘The positivist view of reality has been challenged by scholars from a range of disciplines and backgrounds Whilst acknowledging the existence of external reality it is argued that there are potentially endless ways of knowing, understanding, experiencing and using physical phenomena and objects..... In this view reality is seen as *socially constructed* and variable. Within palliative care research (and within health services research more generally) this position is best represented by what is broadly categorised as "interpretativist" or "qualitative" research’ p5 (emphasis original) (ibid).

Their solution is a pragmatic one, suggesting, I think rightly, that ‘there are no ‘best’ or ‘worst’ methods’ p7, but then taking a thoroughly instrumentalist view of the solution.

‘In practice researchers are unlikely to decide upon their philosophical principles and base their selection of research topic on these. In palliative care, research topics are often practice based and usually problem-led. Methods must be selected in the light of the research problem, the speed with which results are wanted, the use to which they will be put and the resources available’ p8 (ibid).

As a clinician I agree that research must be conducted pragmatically, it is however disappointing that a publication of which David Clark, one of the authors and series editor, felt 'marks a new maturity for palliative care research endeavours and at the same time points the way for further innovation and methodological refinement' p.ix (Clark, 2001), did not feel it necessary to explore the philosophical basis for palliative care research in greater depth.

Danermark et al (2002) agree with Field et al. (2001) that one method should not be privileged over another; however their reasons for suggesting this are completely different. They suggest the preferable way of conducting social research is by adopting a 'critical methodological pluralism' p150 (Danermark et al. 2002). This approach emerges from a clear ontological and epistemological position. They disagree that epistemology should *not* be held above practical considerations and as such take issue with those who advocate a pragmatist philosophical position, expressing their concern that 'there is great risk that some conclusions will be drawn that cannot be drawn from the application of a particular method unless you have made the ontological base clear' p152 (ibid). There is always an implicit ontological assumption which generates a particular research question. Arguably it is preferable that this is made known than to leave it unexamined.

The basis for critical methodological pluralism is a depth realist ontological view. Danermark et al. (2002) also draw on Layder's theory of domains to provide this, pointing out that the domains were in fact originally developed as a research map, to link in concepts of the ontological layers of society with research strategies and methodologies and to overcome what Layder saw as the inherent division of labour between social theorists and researchers (Layder, 1993). The domains form a 'flexible framework of ideas' to aid in the process of research, not imposing itself on the data, but providing 'possible lines of enquiry or explanation', a process Layder (2006) terms 'adaptive theory' p292. Domain theory cannot be reduced to the production of testable hypotheses, but as with all general theories should be judged by how effective it is as an interpretive framework and to what degree it enables the development of a deeper understanding of social structures and processes (Danermark et al. 2002).

The research methods chosen for any study should not just relate to the empirical issue under question, but should be linked into ontological reasoning. To achieve this, a process of retrodution²⁰ should be undertaken using what is known of the wider issues involved, what has already been discovered through research, specific theories relating to the issue and general theory. The research question and methods can then be refined in the light of the ontological issues which arise as well as more practical considerations.

Critical realism I propose provides a firm philosophical basis for a mixed methods approach to research, which can include both quantitative and qualitative methods which Danermark et al (2002) recommend being renamed 'extensive' and 'intensive' respectively. Carter and New (2004) suggest that quantitative research can elucidate the 'traces of reality' which can form the basis for a more explanatory approach using qualitative methods to search for generative mechanisms. The research process will be undertaken not just with regard to the empirical level or low level of abstraction (as in grounded theory), but by a constant movement between general theory, the data and more specific theoretical insights (Danermark et al. 2002; Layder, 1993).

4.3.8 Final discussion

Despite Corner's challenge to the palliative care community to develop a research paradigm in 1996, it seems that little has been done in this area. There has been little change in the type of research undertaken, although the volume of published studies has increased (Kaasa et al. 2006) and interesting and useful developments in specific methodologies have been made (Christakis, 2006).

I suggest that defining a robust philosophical basis for an evidence base in palliative care is necessary and I propose that critical realism can provide this and critical methodological pluralism could be a useful paradigm for its research. EBM as currently conceptualized makes the mistake of privileging RCTs as the gold standard for evidence of effectiveness, based on positivistic philosophical assumptions of linear causality, which have been rejected as untenable in arguably all academic

²⁰ Retrodution is a form of inferential argument which starts with some phenomenon, or pattern, and poses the question "what sort of process, mechanism, agency, and so on, if it existed, would have this phenomenon as its consequence?" The conclusions are not logically necessary, but it offers a rational process for devising candidate explanations"p185 (Benton and Craib 2001)

disciplines apart from medicine. However, the answer is not in adopting a pragmatic approach in which ontological and epistemological considerations are not important, since no amount of methodological rigour can make up for a faulty philosophical basis for research.

Baert (2005) criticises critical realism for putting up ‘straw man’ arguments which caricature others as ontologically naïve suggesting that no-one holds extreme views. Whilst this might be true in social science in general (as graphically put by Byrne, (1998) who declared, ‘positivism is dead. By now it has gone off and is starting to smell’ p37) in support of critical realism, I would say that EBM illustrates that the positivist paradigm is alive and well, within health science, and that palliative care needs to argue strongly against being caught in its strictures. Critical realism provides a robust intellectual framework on which to do this,²¹ which has advocates in health sciences including: nursing (McEvoy and Richards, 2003; Wilson and McCormack, 2006), health promotion (Connelly, 2001), public health (Connelly, 2005), mental health (Fulford and Colombo, 2004) and as a method of adopting a realist approach to interpreting RCTs (Connelly, 2004).

Critical realism has been used as an approach to action research as explored by Winter and Munn-Giddings (2001). Whilst action research is frequently associated with a relativist position e.g. Greenwood and Levin (2005), its original roots lie in a more positivist approach with the work of Kurt Lewin in the 1940s (Hart and Bond, 1995). In their review of approaches to action research Hart and Bond (1995) demonstrate that action research may fit into a variety of philosophical frameworks for research. However, many would argue that what makes action research a distinct approach should be its central concern with the empowerment of research participants (Kemmis, 2001). Collier (1994) argues that a critical realist understanding of social systems can be emancipatory since the knowledge emerging enables oppressive social structures to be challenged. There is therefore a resonance between action research and critical realism; indeed critical realism can potentially enhance the emancipatory work of action research. In chapters 5 and 6 I will illustrate the importance of a depth realist approach to empowerment of patients and professionals

²¹ Robbins (1998) does make a very important point that it is not easy to persuade policy makers that they cannot have simple predictive science. However, it strikes me that the intellectual debate is still worthwhile and will produce outcomes which help our understanding and our teaching.

within community palliative care. This has also been an important focus for the ongoing development of the community of research practice of palliative care practitioners as described in Section 7.6 (page 301).

Hence, crucial to the proper understanding of the issues faced by palliative care patients and therefore that which lies at the basis of providing robust and responsive health care interventions for them, is a proper understanding of the depth of social ontology. I have argued for the use of Layder's domain theory. This seems well respected by social theorists and researchers (Danermark et al. 2002; Pyoria, 1998; Kilminster, 1998; Williams, 1997) and it draws on the strengths of a wide range of social theories, using insights gained from many traditions, but synthesising these in a way which is thoroughly realist and insists on seeing social reality in all its complexity. For these reasons I have judged it to be an excellent general theory, providing a methodological basis from which to work as I explore firstly issues surrounding the emergency admission of palliative care patients into hospital in Chapter-5 and then the support needs of HCAs who work to enable patients to remain at homes in Chapter-6.

As a clinician researcher and leader of a community palliative care team involved in research, I agree with Field et al. (2001), who argue that palliative care research needs to be thoroughly practical in its approach. Using a critical realist approach I will demonstrate that it is possible to generate research findings which not only assist in the development of local services, but which also produce useful theoretical insights to add to the evidence base for palliative care.

Chapter 5 – A Multi-method Study into the Reason for Admission of Palliative Care Patients into Hospital Beds

5.1 Introduction

Chapter-1 introduced the concept of continuity of care for the palliative care patient in the community. The patient is potentially faced with many complex issues in a rapidly changing clinical and social situation, many of which may be unpredictable even with good care planning. In order for holistic care to be delivered to the patient a multidisciplinary approach needs to be taken, at the root of which is the ‘supportive triangle’ of GP, DN and Macmillan nurse (Burt et al. 2005). A review of community palliative care including the history of its evolution was described in Chapter-2.

Whilst palliative care patients spend the majority of the last year of life at home, most are admitted to hospital at some stage. Some of these admissions will be unplanned, i.e. not elective admissions for investigation or treatment. Movement of patients from home to hospital can be seen to be a break in ‘continuity of place’ (Rogers et al. 2007) and has been reported to be at times related to lack of suitable services in the community (Herd, 1990; Thorpe, 1993; Thomas, 2003; Munday et al. 2002). A systematic review of published papers which report the reasons for admission to hospital was given in Chapter-3, revealing that no qualitative studies had been reported which had the primary aim of specifically and systematically examining these issues.

In this chapter I will describe a multi-methods study entitled ‘Reasons for emergency admission of palliative care patients’, which was undertaken in 2000-2001 subsequent to the audit described in Chapter-1 (Section 1.6 page 34) and within the same hospital. The first part of the study is a survey of palliative patients admitted as emergencies over five week long periods spaced over six months. The second part is a qualitative interview study in which a number of patients and carers identified in the survey were asked to recount their experience using a critical incident and narrative approach. Finally, key informant interviews with health care professionals involved in the process of admission or in the care of palliative care patients in the community were undertaken. These studies provide an account of the issues which lead to patient admission as well as giving insights into community palliative care in the city. The range of research questions and techniques employed allowed a detailed

examination of the immediate causes of admission and the contextual factors surrounding it, from the perspective of patients, carers and health care professionals. This has enabled a depth of description to emerge which would not have been achieved with a single study and from this an understanding of the ontological depth of the relevant issues.

I undertook this study as a lone researcher-practitioner rather than as part of a community of research practice (as discussed in Section 7.6 page 301), however it enabled me to explore the potential of practitioner research in exploring complex contexts in community palliative care, which I develop further in the next chapter.

In the first part of this chapter I will explore the use of the critical incident technique (CIT) in qualitative research. I will then briefly explore the nature of narrative in patients with chronic and life threatening illness. After this I will describe the methods and results of the three empirical studies undertaken, and finally I will explore the issues of power which emerged from the studies using Layder's domain theory.

5.1.1 Critical incident technique (CIT)

CIT was originally developed by Flanagan (1954) to examine the work of military pilots during World War Two. When trainee pilots were judge to be unsuitable for the role, the reasons given were often very broad such as 'lack of inherent flying ability' or 'unsuitable temperament' p328 (ibid). In an attempt to make assessments 'objective,' CIT focused on incidents or sets of incidents which provided the best opportunities for judgements to be made. The main elements of a critical incident being expressed thus:

'By an incident is meant any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act. To be critical, an incident must occur in a situation where the purpose or intent of the act seems fairly clear to the observer and where its consequences are sufficiently definite to leave little doubt concerning its effects' p327 (ibid).

Central to CIT was a method of judging the issues arising in a critical incident, utilizing what were considered 'objective criteria', consistent with the normative

scientific approach of the day. These criteria were confirmed by demonstrating that two observers would make the same report. Thus Flanagan asserted that the CIT...

‘..rather than collecting opinions, hunches, and estimates, obtains a record of specific behaviors from those in the best position to make the necessary observations and evaluations. The collection and tabulation of these observations make it possible to formulate the critical requirements of an activity’ p355 (ibid).

In the 1940s and 1950s Flanagan developed the technique to examine other issues in the aircraft industry and other organisations, using a largely quantitative and positivist approach. CIT has more lately been performed using phenomenological approaches in organisational research (Chell, 2004) and since the early 1990s has been employed increasingly in nursing, primary and palliative care research (Luker et al. 2000; Robinson and Stacy, 1994; Cox et al. 1993; Keatinge, 2002; Kemppainen, 2000; Redfern and Norman, 1999a; Redfern and Norman, 1999b). Examples include: exploring issues which enhanced or detracted from high quality district nursing in palliative care (Luker et al. 2000); identifying indicators of quality in nursing care from the perceptions of patients and nurses and assessing levels of congruence between them (Redfern and Norman, 1999a; Redfern and Norman, 1999b); and using critical incidents arising from palliative care situations in the community to draw up primary care practice guidelines (Robinson and Stacy, 1994). As well as interviewing a key informant about the event – i.e. *retrospectively* – CIT may be performed *directly*, by observing the event itself (Redfern and Norman, 1999a). This however has the disadvantage that the observer needs to be present at an event the timing of which may be unpredictable. The direct technique has been successfully used to observe critical events on a ward during an action research study into the care of patients with dementia (Keatinge, 2002).

Reported advantages of the technique are that it enables complex situations to be examined and a rich picture of the event to emerge; examining a single event focuses the interview and leads to a description of an event in a time-linear fashion which is then open to causal analysis; in addition the actions and behaviours of the individuals involved and the outcome of the event can be examined in context (Kemppainen, 2000). The researcher thus has an event into which they can probe and the interviewee has an incident on which to ‘hook their accounts’ p47 (Chell, 2004).

Given the focus of the technique on a discrete event, interviews can often be quite short and do not typically have to be longer than 15 – 20 minutes (Kemppainen, 2000). Analysis is also facilitated because the event *itself* becomes the basis for analysis (Flanagan, 1954).

The advantage of using CIT in this study was that there was a clear event on which the research participant could focus, the research question allowed a narrative approach to be taken and the interviews could be brief which was a particular advantage for palliative care patients.

5.1.2 Narratives in research

Narrative research is an important method for exploring social and temporal phenomena. Examples of narrative methodologies are given in Box 5-0 page 167a. The systematic review of reasons for the emergency admission of palliative care patients in Chapter-3 illustrated the relative strengths of quantitative and qualitative approaches to exploring these events. Since emergency admissions are discrete events their complexity can be explored qualitatively through recording narratives surrounding the event, particularly the patient's narrative, i.e. they are an aspect of the 'illness narrative'. Illness narratives have been explored by several sociologists and anthropologists who have researched the experience of the patients with chronic illness (e.g. Bury, 2001; Williams, 1984; Frank, 2004; Kleinman, 1988).

In the next section I will consider some of the methodological issues which arise from exploring the illness narratives described in this chapter.

5.1.2.1 Illness narratives

It is useful to be reminded of the basic function of narrative:

'Narratives most simply put are stories that relate the unfolding of events, human action, or human suffering from the perspective of an individual's lived experience' p221 (Muller, 1999).

Rather than being merely transmission of factual information regarding an event narratives convey the meaning and interpretation which the narrator attaches to it (Bury, 2001). That narratives form a ubiquitous part of life is evident in the genre of biography and autobiography, giving narrative accounts of whole lives. However

- 1) **Illustrative Narratives:** using narrative to illustrate personal experience of health and illness - e.g. patient narratives from a range of illnesses including cancer, heart disease and serious and potentially fatal illness, collected as a resource for patients, carers and health care professionals. Narratives are not analysed, but extracts are isolated and used illustratively www.DIPEX.org.
- 2) **Narrative analysis:** The following are examples of narrative analysis used in health and social care
 - a) Discourse analysis of narrative (e.g. used to analyse text of a medical consultations): detailed analysis of the text including length of the interaction, pauses, immediate contextual factors etc. “The aim is to reproduce the dialogue down to the last ‘um’” (Elwyn and Gwyn, 1999) p167.
 - b) Classification of narrative type: This is used by Frank (2004) and is described in Section 5.1.2.1 (p167) where three ideal types of end of life narratives are defined from patient interviews – quest, restitutive and chaotic.
 - c) Identification of type of narrative form: Kendall and Murray (2004) transcribing narratives of patients with heart failure explored their form as narrative poetry. Presenting them in this form created a powerful resonance for patients and health care professionals alike.
 - d) Exploration of how personal narratives interact with available cultural scripts: linking personal to collective narratives - e.g. exploring personal experience of ‘social mobility’ (Lawler, 2002).
- 3) **Qualitative analysis:** Narratives may be collected and analysed using standard qualitative methods
 - a) Murray et al (2002) analysed the interviews from which the narratives described in 2c (above) emerged, using a standard qualitative approach. They explain “using both approaches set up a valuable dialogue between them, allowing us to transfer the insights gained from each” (Kendal and Murray, 2004) p68.

Box 5 – 0 – Examples of the ways narrative are collected and analysed in research

narratives are more than just a mode of social communication, they are the way that we understand and view ourselves and make sense of our experience (Somers, 1994).

Narratives emerging in chronic illness are thus an expression of the patient's identity not merely a description of their experience. However, in so far as one has control over one's own story, from the patient's point of view the illness narrative is very unlikely to be the narrative they would have chosen for themselves. Thus Bury (1982) has introduced the concept of 'biographical disruption' in chronic illness, which he defines as that 'which fractures [the] social and cultural fabric, exposing the individual to threats to self identity and a potentially damaging loss of control' p124 (Bury, 1997). This disruption is manifest in numerous and multiple ways: - through persistent or recurrent symptoms each of which potentially hold significance and act as reminders to the patient of their state of ill-health, losses in terms of physical function and social interaction, and the curtailment of occupational and leisure activities - all leading to increased reliance on others and inherent uncertainty regarding the future. Hence:

'The chronically ill live at the margins. Even a modest change can be the difference between acceptable, if frustrating, quiescence, and an eruption of symptoms distressing enough to yield a condition that is unacceptable and not infrequently, dangerous' p44 (Kleinman, 1988).

To use a word processing analogy, for the chronically ill their narrative is continually and randomly punctuated with deletions and the capricious pasting of unwanted, alien and threatening text, entirely beyond their control, leaving the plot uncertain and potentially destructive.

Since narrative is a fundamental feature of existence, from this sense of disruption and uncertainty, patients and their families need to reconstruct a coherent text both in terms of understanding the illness in the light of past social experiences and achieving a new sense of life course and self identity (Williams, 1984). Furthermore, since experience is always evolving, narrative reconstruction is a continuous process with patients drawing on multiple sources which are culturally available to them. Since for the chronically ill, life becomes 'colonised' by health and social care interventions this narrative reconstruction typically takes the form of an 'ongoing

dialectic between lay “experiential” narratives of illness and professional “expert” narratives of disease’ p115 (Scambler, 2002).

Frank has suggested that illness narratives at the end of life follow three basic structures. Firstly, the ‘restitutive’ narrative which accompanies a biomedical focus on ‘fixing’ the problem to achieve a cure or at least prolonged survival, and being typically illustrated by metaphors of ‘fight’ and ‘battling’; secondly the ‘quest’ narrative, in which the patient is aware of their dying and seeks to achieve a sense of purpose in it with the story often taking on a heroic quality; whilst the third he defines as the ‘chaotic’ narrative where ‘words never quite form stories because there seems to be no narrative going anywhere, only accumulations of suffering’ p140 (Frank, 2004). Whilst these structures are identifiable within dying narratives, since they are ‘ideal types’, they rarely exist in pure form.

Emergency hospital admission commonly accentuates the feeling of events being out of control, e.g. Hinton, (1994b), Worth et al. (2006), Rhodes and Shaw (1999), Skilbeck et al. (1998), since these event are unplanned and potentially represent a worsening of the disease state for the patient. Thus, emergency admission fulfils the conditions for a further biographical disruption, through its inherent uncertainty in terms of potential outcome and significance for the rest of the patient’s life. The life course which palliative patients weave is precarious, even for those whose narrative takes on the form of ‘restitution’ or ‘quest’, to use Frank’s classification. Thus narratives of the emergency admission as recorded in this study arise in the context of this fracturing and need to be understood as such.

Since narratives are co-created in the space between individuals (Williams, 1984), it is through the process of discourse that narrative reconstruction is facilitated. It therefore had to be born in mind during the interview that narrative reconstruction is likely to have been ongoing. This would be made all the more likely since from my experience of working as a clinician in the same hospital, I was aware that many patients would have had little opportunity to recount their story (apart from in narrow biomedically focused terms and in response to closed questioning). Thus the interview could have been the first opportunity for many to recount the broader story of their admission experience. Whilst enabling narrative reconstruction was not the primary intention of the research, since this was likely to be a task which the patient

was undertaking at the time, the interview was potentially going to have an impact on the reconstruction. This could have had methodological implications, since the narrative would be in a state of flux such that the story given on one day might not have been repeated on the next. Although, it could be argued (from a positivist perspective) that this would lead to the narrative being more representative of the ‘actual’ event since it had not undergone iterative reconstruction, it conversely raises the question of what constitutes a ‘true’ narrative account.

Finally it needs to be highlighted that narrative reconstruction is work and involves effort. At a time when the patient was likely to be fatigued and have low energy reserves this raises ethical issues regarding the interviews since the effort expended in narrative reconstruction by terminally ill patients has been noted to be considerable (Exley and Letherby, 2001).

5.2 Reasons for emergency admission of palliative care patients

5.2.1 Introduction

Whilst the proportion of deaths occurring in hospital, high levels of bed usage amongst patients in their last year of life, and questions regarding the appropriateness of admitting patients with advanced disease into acute hospital beds have all recently been raised as important issues, little research has been undertaken in this important area. Whilst the study presented here was undertaken to provide insights into this important area, it also had two local aims. First, to understand the reasons for patients being commonly admitted following an emergency ambulance call and bypassing GP services, as highlighted in the audit described in (Section 1.6 page 34), and second, a need to understand the reasons for what were considered unacceptably high admission rates of palliative care patients, so that appropriate community services could be developed. The study was funded by the health authority and was restricted to patients admitted from the city. A geo-social description of the city was given in Section 1.3 (page 23).

The study had three parts:

- 1) A survey of emergency admissions of palliative care patients.
- 2) Interviews with a group of patients identified in the survey.

- 3) Key informant interviews with health care professionals particularly involved in caring for patients who were admitted.

5.2.2 Aim

To investigate the reasons for emergency admission of palliative care patients into hospital beds, through the following research questions:

- 1) Which palliative care patients are admitted as emergencies into hospital beds, what are the characteristics of these patients, and which routes to admission do they take?
- 2) What are the problems faced by such patients in the community which lead them to need admission to hospital as emergencies?
- 3) Which health care professional (HCP) or service do the patients or their carers call? Why do they select that particular HCP and what other options are available to them?

5.2.2.1 Methodological note: mixed methods and triangulation

Whilst this study uses mixed methods, the majority of the data is qualitative, arising from interviews with patients and carers and health care professional key informants, using both individual interview and group interview design. The quantitative study is a survey of emergency admissions, which is mainly descriptive in its approach, although it does include some comparisons between patients with cancer and non-cancer diagnoses. Thus, the project employs a mixed methods design which is consonant with a critical realist stance (Section 4.3.7 page 158); the overarching philosophical approach which I employ. Central to a mixed methods approach is the concept of triangulation, which I will briefly explore.

Triangulation is a term taken from surveying in which the location of a point is confirmed by viewing it from three perspectives. In research it was initially used to compare the results from quantitative studies which explored a common issue but using different research designs (Tashakkori and Teddlie, 1998). Shih (1998) identifies triangulation as having two distinct purposes, firstly ‘confirmation’ in which several different approaches are taken to research the same variable, ‘once a proposition has been confirmed by two or more independent measurement processes, the uncertainty of its interpretation is greatly reduced. The most persuasive evidence

comes through a triangulation of measurement process' [quoting Webb et al 1981] p633 (Shih, 1998). This approach is therefore particularly consonant with a positivist or post positivist stance (Tashakkori and Teddlie, 1998). Secondly triangulation can be employed to enhance understanding and give 'a more complete holistic and contextual portrayal of the unit(s) under study' p633 (Shih, 1998). This latter approach will search for similarities, patterns and relationships, aiming at conceptual validation arising from data contributed by all of the available studies. Thus Denzin and Lincoln (2003) suggest that 'the combination of multiple methodological practices, empirical materials, perspectives and observers in a single study is best understood then as a strategy that adds rigor, breadth, complexity, richness and depth to any inquiry' p8.

Commonly triangulation is viewed as having four distinct types which are attributed to Denzin (Tashakkori and Teddlie, 1998; Williamson, 2005; Robson, 2002):

- 1) Data triangulation - the use of a variety of data sources within a study.
- 2) Investigator triangulation - the use of several different researchers within a single project.
- 3) Theory triangulation - the use of multiple theoretical perspectives to interpret the results of a study.
- 4) Methodological triangulation - the use of multiple methods to study a research problem p174 (Robson, 2002).

Within this study I have particularly relied on data and methodological triangulation as narratives have been compared between patients with various conditions and experiences and results from quantitative and qualitative methods have been used to explore, interpret and enrich emergent themes and insights. Working with co-researchers (as presented in Chapter 6 and 7) has given scope for investigator triangulation within later projects.

5.3 Survey of palliative care patients needing admission

5.3.1 Objective

To survey palliative care patients admitted as emergencies over a five week period, taking note of the number of patients, demographics, disease type, route of admission

and services received in the community, in order to identify their pathways to admission.

5.3.2 Method

5.3.2.1 Definitions

The definition of palliative care patient used for the survey is given in Box 5-1. Emergency admission was defined as any unplanned admission into a hospital bed, in which admission occurred on the day of referral.

Malignant Disease - non curable disease in an advanced stage. Patients may or may not be receiving palliative chemotherapy or radiotherapy.

Non-Malignant Disease - advanced, life threatening and identifiable disease, e.g. respiratory failure on home oxygen, AHA stage IV cardiac failure, end stage progressive neurological disease.

Patients for both groups were judged to be in their last year of life.

Box 5-1 Definitions used in selection criteria for palliative patients

5.3.2.2 Recruitment

Recruitment occurred over four periods of seven days and one of six days. These periods were spread over a six month period from July to December 2000 (see Table 5-1). Weeks were chosen largely for practical reasons – to fit in with work schedules, although spacing recruitment also enabled admissions occurring in different seasons to be examined. However, the time I had available for this study did not allow the study to be spread over 12 months. Spacing each week of recruitment also enabled reflection to take place on issues arising during the data collection so that the method could be adjusted as necessary.

Week	Dates
Week 1	Wednesday 12 th – Tuesday 18 th July
Week 2	Tuesday 12 th September – Monday 18 th September
Week 3	Saturday 7 th October – Friday 13 th October
Week 4	Wednesday 25 th October – Tuesday 31 st October
Week 5	Tuesday 12 th December – Sunday 17 th December*
* It was not possible to collect data for Monday 18 th due to clinical commitments	

Table 5-1 - Sample weeks

The data source used for recruitment was the activity book in the emergency admissions unit (EAU), which had previously been used for the audit (Section 1.6

page 34). This book was scrutinized for patients who might fulfil the criteria for selection and the names and destination wards were recorded. The ward where the patient had been admitted was visited and the patient records were examined to determine whether they met the inclusion criteria. Patients admitted directly onto the oncology ward did not pass through EAU. The names of these patients were recorded in the ward admission book which was also scrutinized to enable eligible oncology ward patients to be recruited.

5.3.2.3 Inclusion criteria

Any adult patient admitted to the general hospital through EAU or admitted to the oncology wards and who were judged to be 'palliative' (see Box 5-1) were eligible for inclusion. I discussed the definition of palliative care which I used in detail in Section 1.2 (page 19). Since there is no clear and robust method for assessing prognosis, I relied on my clinical judgement to make the assessment of whether patients fulfilled the criteria, largely on the basis of previous history. Whilst the majority of case records were available for perusal which included previous diagnostic and treatment history, for some patients no such records were available and a decision had to be made on the basis of the information given on admission and clinical findings subsequently.

5.3.2.4 Exclusion criteria

All patients under the age of 18 were excluded. Patients admitted directly onto the haematology ward were not included. This decision was made following discussion with the ward sister, who was concerned about the daily disruption to ward routines and staff time. This concern is understandable, since for many haematology patients the distinction between curable and palliative is more difficult to assess and I would have needed more guidance as to the palliative nature of the disease. Conversely, the nurses on the oncology ward knew me from my time working clinically on the ward as a palliative medicine specialist registrar and were more enthusiastic about being involved in the study.

5.3.2.5 Practical recruitment issues

Patients were included in the study as soon after admission as possible because some were discharged after a short period; this also allowed interviews to take place close to the event. Selection was at times problematic. Rarely was a clear underlying

diagnosis given in the EAU activity book, e.g. ‘chest infection in metastatic lung cancer’, more likely the diagnosis would be ‘chest infection’ or even and a perfunctory record of symptoms, e.g. ‘shortness of breath (SOB)’. For this reason a large proportion of patients admitted through EAU were followed up and excluded on the ward. Examples of patients who were excluded in EAU were young people admitted following overdose, patients with chest pain admitted to the coronary care unit or patients with surgical diagnoses such as ‘appendicitis’. Thus the process of selection was highly labour intensive.

5.3.2.6 Data collection

Once patients were identified and recruited their details were written on a data capture form which included details of: age, sex, ethnicity, marital status, living circumstances, diagnosis, date of admission, route of admission, GP name, whether seen by DN, Macmillan nurse or other community carer, number of admissions in last year and number of days spent in hospital in last year. Some of this data was available from the hospital written record and other information, such as the number of days spent in hospital was available from the hospital computer system. If data collection from the hospital records was incomplete and the patient or their carer were interviewed I asked for this information directly. I was also able to find relevant information by speaking to clinical staff, particularly the nurses on the oncology ward or the community Macmillan nurses, who often had detailed knowledge of the patient and the services they received in the community. During the course of the study I had the opportunity for some discussions with DNs regarding individual patients. All of these conversations were recorded in my field notes.

Once data collection for the survey was complete, the data including the patient’s hospital registration number, but not their name was entered onto a spreadsheet which was used for analysis. The data capture sheet was filed securely away from all other information which could have led to anonymity being breached. This process normally took no more than 48 hours for each patient. (For full consideration of ethical issues for this study see Section 5.4.2.5 page 187).

The quality of admission records was such that it was difficult to be certain of the exact reason for admission of patients into hospital if these were relied upon. Since 37 (46%) of cases involved interviews with either the patient (30) or relative (7), it

was not considered useful to attempt to categorise the reason for admission from the survey, since this was the function of the qualitative study.

5.3.2.7 Data analysis

Data from the survey were analysed using SPSS v10. Because of the small numbers involved and missing data, descriptive statistics were used largely without testing for statistical significance. For some variables where data was virtually complete because computer records were available (e.g. number of admissions and days in hospital in last year) statistical comparison between cancer and non cancer patients could be made.

5.3.3 Results

A total of 81 patients were identified in the survey with a range of 11 – 20 patients per week (see Table 5-2). 52 had malignant and 29 had non-malignant disease.

	Malignant	NonMalignant	Total
Week 1	9	7	16
2	15	4	19
3	12	8	20
4	8	3	11
5	8	7	15
Total	52	29	81

Table 5-2 - Number of patients admitted per week of study

Table 5-3 shows the admissions on each day of the week for the five weeks. Whilst admissions were spread throughout the day and night the majority were between 10am and 6pm, with a second smaller peak in the evening. Only eight (10%) admissions occurred between midnight and 10am as illustrated in Figure 5-1.

Day	Admissions	Percentage
Monday	11	13.6
Tuesday	9	11.1
Wednesday	13	16.0
Thursday	12	14.8
Friday	9	11.1
Saturday	15	18.5
Sunday	12	14.8
Total	81	100.0
Data collect on only four Mondays		

Table 5-3 - Number of admissions on each week day

Frequency of Time of Admission

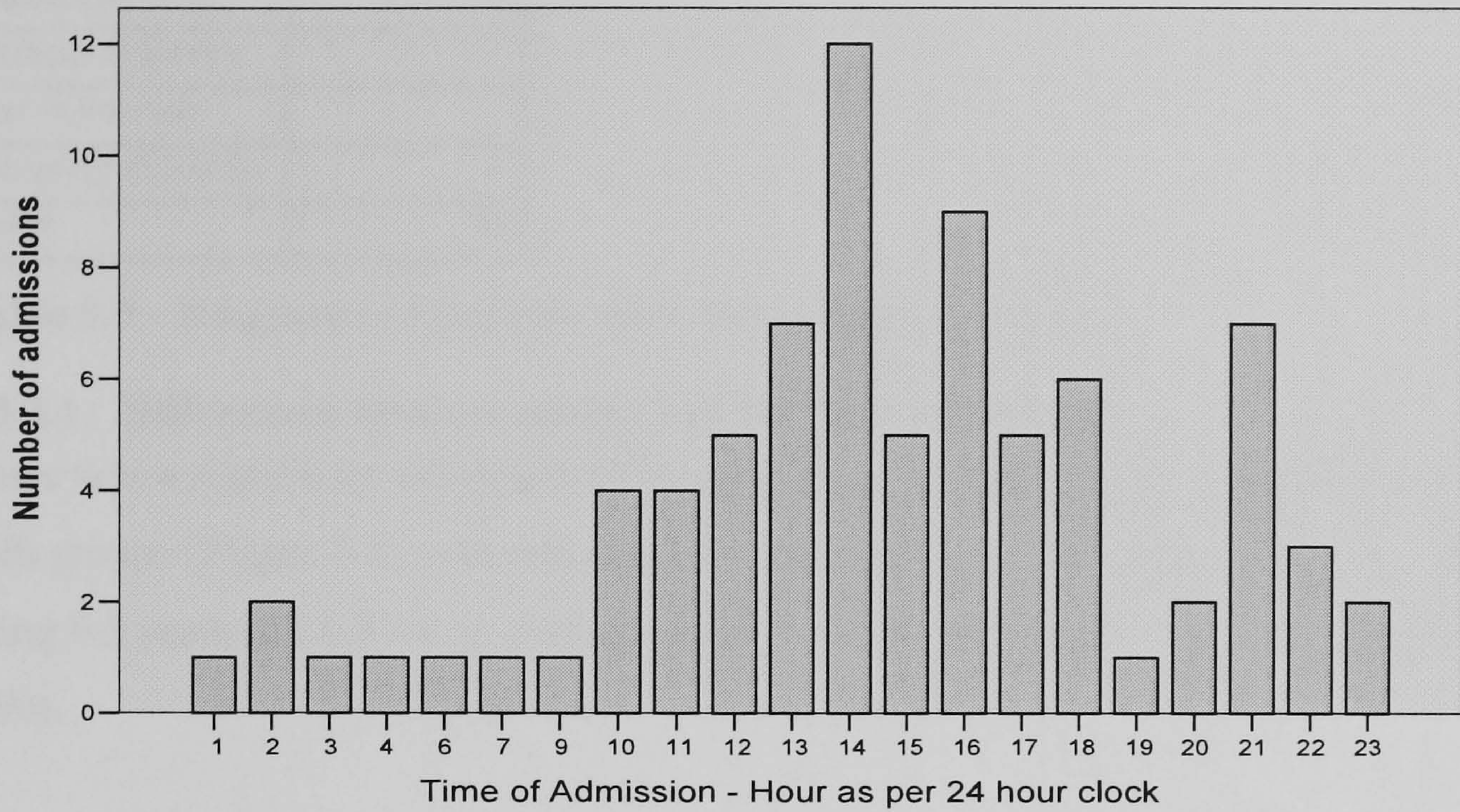


Figure 5-1 - Frequency of time of admission

The commonest malignant diagnosis was carcinoma of the lung (16) followed by prostate (8) and breast cancer (5), whilst the commonest non-malignant diagnoses were COPD (16) and heart failure (6). Full details of diagnoses for malignant and non malignant disease are given in Table 5-4 and Table 5-5 respectively.

Diagnoses	Frequency	Diagnosis	Frequency
Ca Lung	16	Ca Gall Bladder	1
Ca Prostate	8	Ca Rectum	1
Ca Breast	5	Ca Cervix	1
Ca Ovary	4	Ca Vagina	1
Ca Bowel	2	Unknown Primary	1
Ca Kidney	2	Ca Bladder	1
Brain Tumour	2	Ca Uterus	1
Ca Oesophagus	2	Mesothelioma	1
Hepatoma	1	Total	52
Non Hodgkins Lymphoma	1		
Leiomyosarcoma of Uterus	1		

Table 5-4 Diagnoses of patients with malignant disease

Diagnosis	Frequency
Chronic Obstructive Pulmonary Disease	16
Heart Failure	6
Senile Dementia	4
Multiple Sclerosis	1
Cor Pulmonale	1
Fibrosing Alveolitis	1
Total	29

Table 5-5 - Diagnoses of patients with non-malignant disease

5.3.3.1 Differences between cancer and non-cancer patients

There was a significant difference (95% confidence interval) in the average ages of both groups (Figure 5-2) with mean age of cancer patients (64.9 year, range 35 – 89) being 9.3 years (CI 4.2-14.5) younger than non-cancer patients (74.2 years, range 49 – 90).

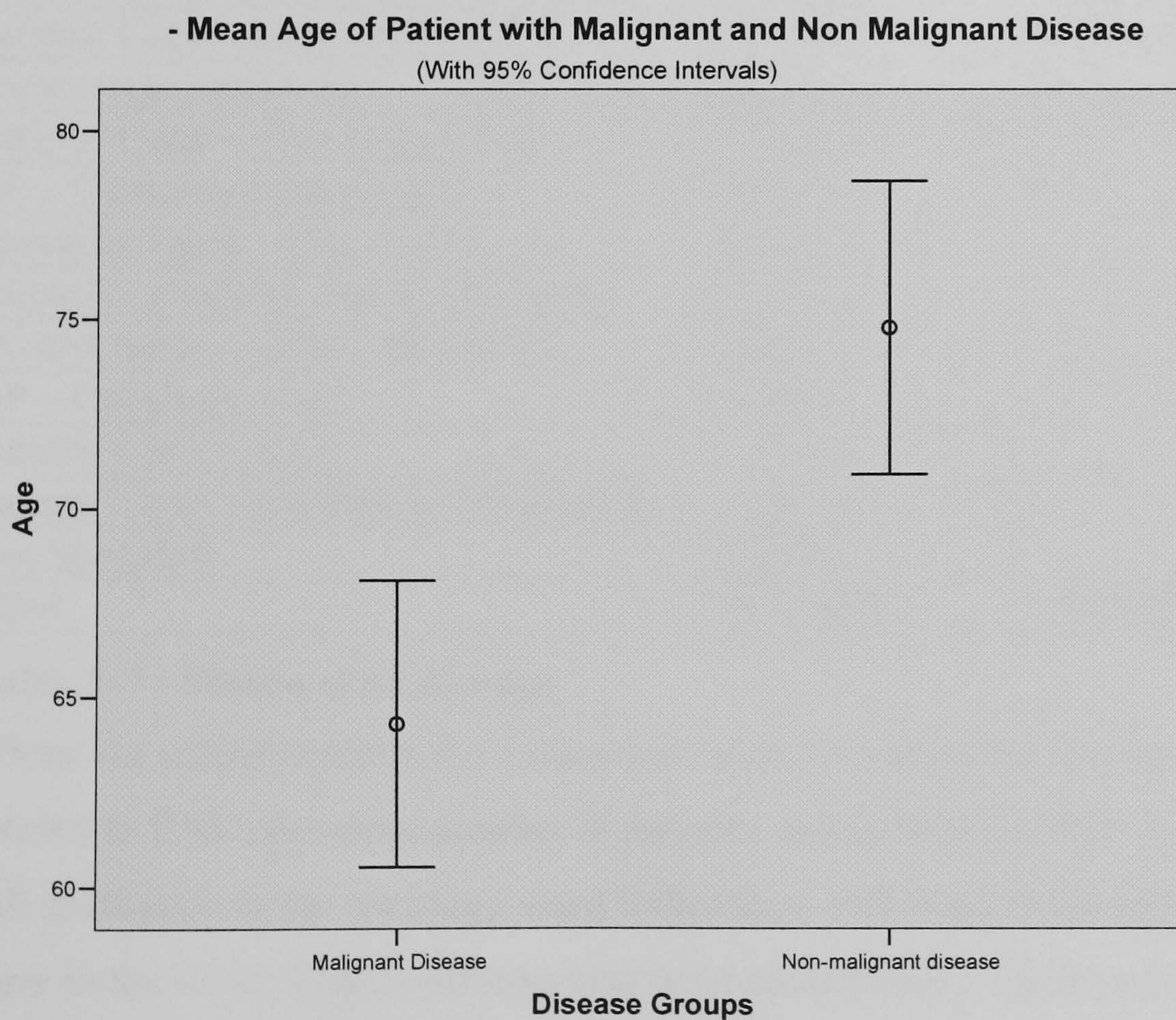


Figure 5-2 - Comparison of ages of malignant and non-malignant groups

Equal numbers of men and women were recruited and although more men than women were in the cancer group and the converse for non-cancer (Table 5-6) this difference was not statistically significant (Chi-square = 2.37, 1 df, p<0.2).

	Gender		Total
	Female	Male	
Cancer	23	29	52
Non-cancer	18	11	29
Total	41	40	81

Table 5-6 - Gender distribution according to diagnostic group

Malignant and non malignant groups differed markedly in their experiences of health services with patients with malignant disease being admitted by eleven different routes, whereas patients with non cancer diagnoses were mainly admitted by ambulance or by their GP, with only one admitted following a clinic visit as shown in Table 5-7.

Mode of Admission	Malignant	Non-malignant
GP – Emergency Admissions (EAU)	18 (35%)	13 (44%)
Patient/ Carer – called ambulance	7 (13%)	15 (52%)
From outpatient clinic	6 (12%)	1 (4%)
Patient/ Carer – Oncology ward	7 (13%)	
GP – Consultant Oncologist	3 (6%)	
Specialist nurse - Oncologist	2 (4%)	
Palliative medicine domiciliary visit	2 (4%)	
District nurse – called ambulance	2 (4%)	
GP – Oncology ward	1 (2%)	
Patient/ Carer – EAU	1 (2%)	
Patient/ Carer – Consultant Oncologist	1 (2%)	
Not Specified	2 (4%)	
Total	52 (100%)	29 (100%)

Table 5-7 - Modes of admission

Whilst for cancer patients the commonest route of admission was through a GP referral to EAU, the same number of patients was admitted either via an ambulance call or directly to the oncology ward following a call from either the patient or their carer to the ward. Cancer patients also were admitted in a variety of other way, for instance: following discussions between the GP or palliative care CNS and a consultant oncologist, or as a result of a palliative medicine domiciliary visit. One patient was admitted following a direct call to the consultant oncologist herself. No such routes seemed to be open to non-cancer patients.

Cancer and non-cancer patients had different experiences of hospital admission, both in terms of the number of admissions and the number of days spent as inpatients in the previous year. Cancer and non-cancer patients had an average of 2.14 (range 0-9, SD 1.833)¹ and 3.67 (range 0-13, SD 3.101) admissions respectively and spent an average 18.45 (range 0-63, SD 16.364) and 34.07 (range 0-106, SD 29.471) days in hospital in the previous year. Mann-Witney U non parametric test, for non-normally distributed samples indicated that both of these differences between cancer and non-cancer patients were significant (see Table 5-8). Multiple regression testing demonstrated that this difference was maintained even when the samples were corrected for the effect of age.

	Days in hospital in last year	Number of admissions in last year
Mann-Whitney U	470.000	469.000
Wilcoxon W	1796.000	1795.000
Z	-2.334	-2.309
Asymp. Sig. (2-tailed)	.020	.021
Mann-Witney U Non parametric test Comparing days in hospital and hospital admissions for patients with cancer and non-cancer disease		

Table 5-8 - Patterns of hospital admission over previous year

There appeared to be a difference between cancer and non-cancer patients in terms of community nursing services received, with proportionately more cancer patients than non-cancer patients receiving DN services (Table 5-9), in addition of the eight patients recruited from care homes, seven had non-cancer diagnoses (4 COPD and 3 dementia) and only one had cancer. Small numbers of patients and missing data for 14 (17%) of them precluded further statistical analysis.

	DN service received	No DN service received	Care Home	Data Missing	Total
Cancer	37	4	1	10	52
Non-cancer	10	8	7	4	29
Total	47	12	8	14	81

Table 5-9 -DN services received

Seventeen cancer patients (33%) were found to have had contact with a community Macmillan nurse whilst 21 (40%) had not and for a further 14 (27%) this was

¹ SD – Standard Deviation.

uncertain. None of the patients with non-cancer diagnoses were known to have seen a community Macmillan nurse or other community CNS.

5.3.3.2 Accuracy of patient selection

As a result of the inherently subjective nature of deciding whether a patient was eligible (i.e. a patient with advanced disease in the last year of life), patients may have been recruited who did not meet the selection criteria for inclusion and vice versa. Whilst making a judgement on the failure to include eligible patients is not possible, 3 months following the completion of the study, a review of hospital computer records was made to determine which patients had died. This revealed that 24/36 (67%) recruited at least 6 months before and 23/45 (51%) recruited 3-6 months before had died, lending some support to the selection process used. Significantly more cancer than non-cancer patients had died (Table 5-10).

	Died	Alive	Total
Malignant	38	14	52
Non-Malignant	9	20	29
Total	47	34	81
Pearson Chi-Square 13.511 df 1 p<0.001			

Table 5-10 - Number of patients deceased 3 months after study

This difference could be explained by non-cancer patients being more likely to be included later in the study, however Table 5-2 shows that this was not the case, with cancer and non-cancer patients being recruited equally through the period. I would suggest that this difference in mortality probably illustrates the inherent difficulty in estimating prognosis in a patient with a non-malignant condition rather than a problem with the definition or method used for sampling.

5.3.4 Discussion of survey

More palliative patients admitted during the five sample weeks had malignant rather than non malignant conditions. Whilst this may seem implausible since more patients die of chronic non malignant than malignant disease, it is likely to result from the difficulty inherent in making a diagnosis of terminal non-malignant disease in a relatively unselected population of patients. For instance many non-cancer patients were excluded because they had no clear diagnosis. Some of these might have been included if diagnostic information had been clearer, however, many of this group were elderly with multiple co-morbidity, none of which was 'terminal' in itself,

falling into the category marked by the trajectory of 'prolonged dwindling' p1008 (Murray et al. 2005). It is for this group particularly that the borderline between care of the elderly and palliative care is blurred. Although their needs are great and should be addressed (Seymour et al. 2001), it was beyond the scope of the study to include this group.

The commonest cancers represented in the study were lung, prostate and breast, consistent with the cancer incidence and prevalence in the UK at the present time. Non-cancer patients being on average around 10 years older than cancer patients has been noted by studies of both non-cancer patients in general (Addington-Hall et al. 1998b; Exley et al. 2005) and of heart failure (Murray et al. 2002) and COPD patients in particular (Edmond et al. 2001).

Cancer patients in this study seem to have access to more services, reflected in the increased number of routes open to them in seeking help prior to hospital admission. This seems to be largely a feature of direct access to the oncology ward and community services from palliative care CNSs and doctors. In addition they seem more likely to have access to DN services consistent with findings in other studies and discussed in the systematic review of reasons for admission in Chapter-3. In addition non cancer patients had statistically more admissions and days in hospital in the year before recruitment than cancer patients. Since more patients had COPD and heart failure in this group and these patients are particularly vulnerable to a 'revolving door effect' as their conditions destabilize in the community (Roberts et al. 2002; Brown and Grey, 2000), this is not a surprising finding.

A limitation of this survey was the incomplete nature of the data collected, particularly regarding community services. In addition, small numbers of patients in each group precluded any subgroup comparisons in each group, thus it is not possible to comment on difference between patients with chronic cardiopulmonary disease and dementia, or between different cancers. Inherent difficulties in patient selection arise from the lack of adequate indicators of prognosis particularly for non-cancer patients (Fox et al. 1999).

5.3.5 Conclusion

This study is useful in indicating the number of emergency admissions into hospital for patients with advanced end stage disease over five weeks spread over 6 months.

Its findings are supported by many of the issues revealed in the systematic review of palliative care emergency admissions, particularly regarding the difference between cancer and non-cancer patients. However, in common with other quantitative studies it is likely to conceal the complexities of patient experience regarding the admission process and the services received before admission. Exploring the complexities relating to emergency admissions, particularly the reasons for patients being admitted in the manner that they were, was the main focus of the interview study in the next section.

5.4 Critical incident interviews with patients identified in the survey

5.4.1 Introduction

Having identified palliative care patients who had been admitted as emergencies in the survey, I conducted interviews with them to explore the reasons for admission, or with their carers, particularly if the patient was too unwell to be interviewed.

It was during these interviews that the clinico-social problem encountered, the decision making process involved in seeking help and the subsequent events which led to the patient's admission could be explored in depth. These critical incident interviews therefore form the central part of the project to investigate reasons for admission, providing depth to the breadth identified in the survey. The interviews and the survey also raised questions regarding the role of health care professionals involved with these patients both in the community and the hospital, which I was able to explore with key informants in the final section of the project, which will be presented later in the chapter.

5.4.2 Methods

5.4.2.1 Objectives

To explore with patients or an informal carer the events leading up to emergency admission including: problem faced, the decisions they took, the process of admission and any contextual factors relevant to admission.

5.4.2.2 Recruitment

Any patient who was identified in the survey and who consented to be interviewed was included. A relative was interviewed if the patient was too unwell or if the patient requested it. If the patient was judged to be close to death, neither the patient nor relative were approached.

5.4.2.3 The structure of the interview

The whole event from the time the problem occurred which necessitated admission until the patient arrived in hospital was understood as the ‘critical incident’. It consisted of four parts:

- 1) The patient (and carers) faced a clinico-social situation (a symptom, collapse, inability to cope at home etc).
- 2) Either a health care professional or ambulance was called, the health care professional attended as a routine visit or the patient attended the GP surgery or consultant clinic.
- 3) A decision was taken for the patient to be admitted.
- 4) The admission took place.

The patient or carer was asked to provide a narrative of the critical incident, starting with the development of the clinico-social situation. Patients therefore had clear signposting to enable them to proceed with their story. During the interview the patient or carer was prompted to continue if necessary by being asked “can you explain what happened next?” A picture was then built up of the whole incident from the patient or carer’s memory including the sequence of events and their own interpretation of why the incident unfolded as it did. Also the interviewee would be asked to give reasons for a particular decision (e.g. calling the ambulance), and any other actions which they considered or tried. The incident formed a focus to which the interviewee could always be brought back.

The narrative also enabled an exploration of wider services and other issues which the patient faced. These were frequently volunteered by the patient without prompting when they considered them important contextual issues with explanatory value. An example arose in the first interview, undertaken with a 75 year old man who was admitted with an acute exacerbation of COPD as noted in my field notes:

.....wife is an invalid with angina. They have tried to get a chairlift installed for several months without success. She feels she cannot cope if he is unwell and not in hospital (*Patient 1*).

He went on to express frustration at the failure of social services to provide what was needed and with his GP for not having sent him in on the morning of admission. The

patient had subsequently called for an ambulance in the evening as he felt he was worsening.

At other times the narrative provided a platform from which to explore issues if not volunteered; for example asking “you mentioned your GP visiting when you called – do you have any other services in the community?” This prompted the patient to mention the DN or Macmillan nurse, or would provide an opportunity for clarification, e.g. “you haven’t mentioned the district nurse – do any district nurses visit you at all?” The flow of the interview can thus be diagrammatically portrayed as in Figure 5-3.

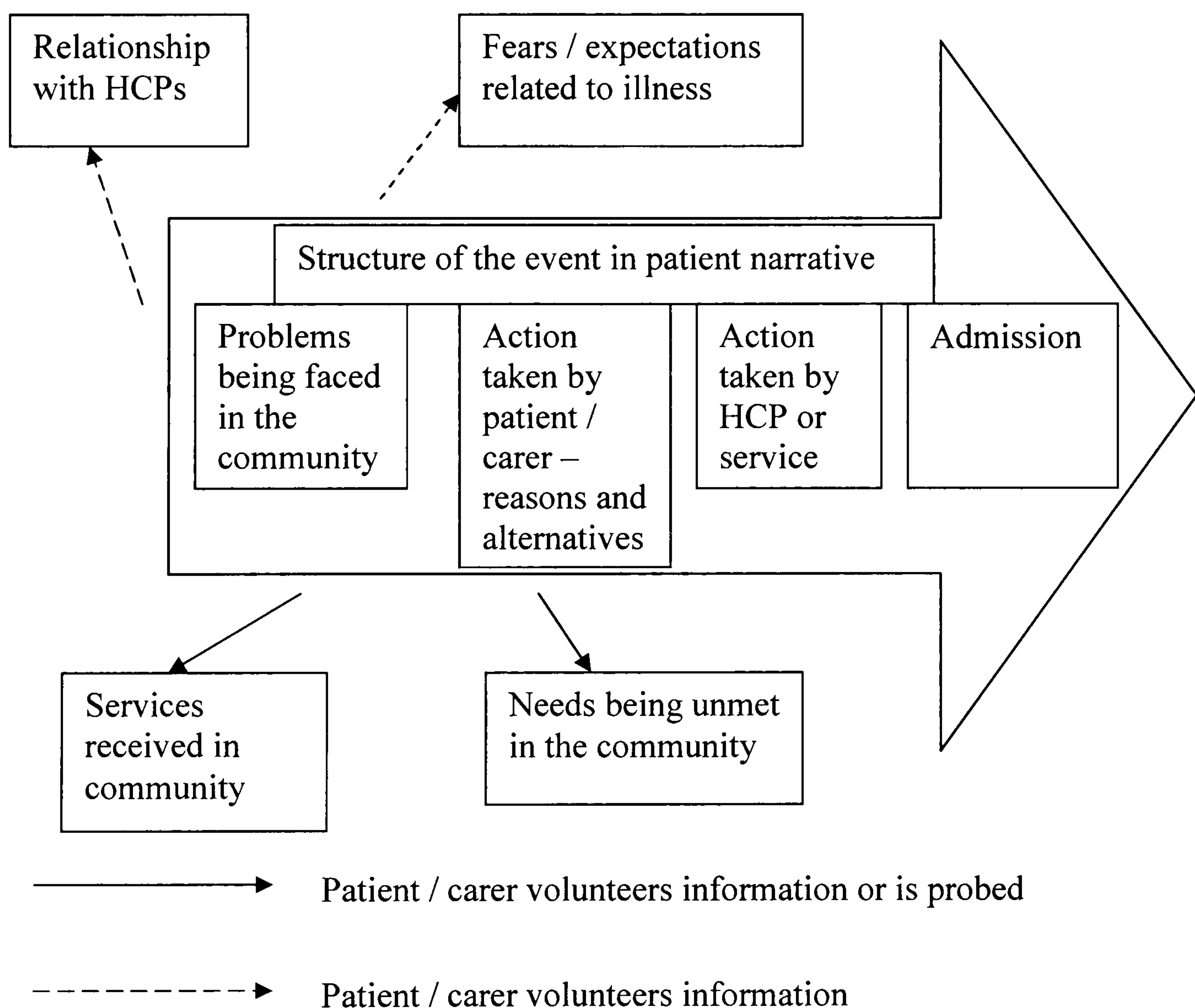


Figure 5-3 Critical Incident Interviews for Emergency Admissions

The critical incident was used to explore wider issues. Certain of these were probed for if necessary, i.e. issues within the block arrow and information about services received and needs which were unmet. However I did not directly explore patient and carer satisfaction with health care professionals and their fears and expectations, although these were often volunteered, particularly as a result of probing for

alternatives to the decision they made which led to admission. Whilst these issues were of interest, constraints relating to the patient's health status and other practical aspects such as the need to record the narrative manually precluded a lengthy interview (discussed in the next section).

5.4.2.4 Practical issues relating to interviews

Patients with serious illness and near to the end of life are usually in a poor state of health, especially after emergency admission to hospital. This raises ethical issues concerning whether this group should be involved at all in research. However, in order to understand the reasons (i.e. context and triggers) for hospital admission, an interview study undertaken during or as soon after the event as possible is arguably the best method of research. In addition, these issues are likely to encompass many important factors interrelated in a complex network, which requires an in depth exploratory interview technique to uncover them. Therefore the dilemma presented by the need for deep exploration and the patient's condition, which precluded long and complex interviewing, required careful consideration. Fortunately, the critical incident technique does provide a method which can reveal important issues rapidly and effectively; however I was unable to explore many interesting and potentially important issues and needed to use a sensitive approach to ensure that the patient was not being stressed or fatigued by the process.

The literature on critical incident interviewing suggests that these are ideally audio recorded to allow later analysis of a transcript (Kemppainen, 2000). However, for a brief interview with a patient who is in a hospital bed, taking them to a quiet room is neither feasible nor acceptable. In addition at the time of these interviews recording equipment was either too cumbersome and intrusive to be used at a the bedside, or the sound quality was too poor for the recording to be of any use. This was confirmed in a test situation on the ward at the commencement of the study.²

Therefore the interviews were recorded manually by taking notes, with sections recorded verbatim if these seemed particularly pertinent or illustrative. Undoubtedly this presented a compromise and a situation which necessitated a rigorous reflexive process to ensure that the findings from the interviews were as robust as possible.

² This is no longer a problem with the new Olympus DM-10 which I have used in more recent studies.

5.4.2.5 Ethical considerations for the emergency admissions studies

Conducting research projects with palliative care patients presents particular ethical issues including: taking time from them and their relatives when time is short and precious; their vulnerability and reliance on others may make it difficult for them to refuse to take part; cognitive impairment is not uncommon, therefore some may not understand the implications of research fully before agreeing; they are unlikely to personally benefit from the results of the research and the research may intrude on sensitive territory causing them distress (Addington-Hall, 2002; Jubb, 2002). All of these issues were pertinent for this study but in addition these patients were frequently unwell and easily fatigued, heightening many concerns. Conversely however Small and Rhodes (2000) point out that ‘mechanisms that aim to increase the effectiveness of user “voice”’ are appropriate ways of enabling ‘user empowerment’ p76 in contexts where user choice is limited. These interviews could be seen as fulfilling this criterion. A recent study also lends support to the assertion that patients at the end of life are often keen to be involved in research (Kendall et al. 2007).

As well as evidence that in general patients are keen to be involved in research, we also had evidence from the audit previously undertaken that patients in this situation were keen to be interviewed (Section 1.6 page 34). These factors seemed to balance out the potential negative effects presented by the study making the overall approach ethical. However it was important to be aware of these ethical issues and to continuously monitor for any distress, bringing the interview to an end if evidence of this was apparent.

To ensure that patient fatigue was kept to a minimum the interviews were short, between 10 and 20 minutes, focussing on the main issues as described above. They were undertaken at the patient’s bedside at a time suitable to the patient to avoid disruption as far as possible. Patients who were too ill to be interviewed were not approached. I made the judgement on this by reviewing the patient’s hospital record and discussing the patient and the aims of the study with the senior nurse on the ward. An advantage of being experienced as a clinician in palliative care was my experience in broaching sensitive areas, conversely, my status could potentially make patients feel unable to refuse to be interviewed. To guard against this I was careful to

stress that I was conducting the interview as a researcher rather than a physician, and to highlight prominently the voluntary nature of the interview.

If any distress did occur during the interview I was prepared to stop the process, although in the study no interviews were terminated because of this. One patient did cry as she described the events leading up to admission, however, she was keen to carry on with the interview once she had regained her composure and therefore I considered it important to do so. If through the interview it became apparent that the patient had issues needing further exploration and support, I would offer a visit from one of the hospital palliative care team as a follow up, who I would contact directly on behalf of the patient. This was necessary on several occasions.

Confidentiality was maintained by ensuring the data was kept safe and identifiers were removed from the data. No transcribers were used as the interviews were not recorded electronically; therefore no other person was involved in processing the raw data.

All of these issues were considered in the research design, which was given approval by the local research ethics committee (LREC) and the hospital research governance committee.

Informed consent was obtained in the usual way: through the use of an information sheet, spending time explaining to the patient the aims of the study, answering their questions and obtaining signed consent. The process of informed consent however did lead to ethical challenges in itself. Whilst most patients approached were very keen to recount their story and seemed to have no difficulty with understanding the purpose of the study, the initial information sheet, although brief (one side of A4), was too long for patients to read. Two in particular wanted to talk to me without signing the consent form, seemingly puzzled by the formality of the process for such a short interview. It seemed to be paradoxical that the part of the study which seemed to potentially cause the most distress was the consent process which had closely followed ethics committee guidelines. Therefore the information sheet was rewritten in a simpler format with a larger font for which ethics committee approval was obtained. Using the information sheet as part of the discussion around the nature of the study was also preferable to giving it to the patient for them to read on their own, as this also seemed to tire them less. Our experiences concerning the ethics of

consent in this study were presented as a poster to the BMA Narrative Research Conference 2004 (Munday et al. 2004). Information sheets and abstract for the conference are given in Appendix 1 (page 311).

Specific patient consent was not obtained for the survey. It would not have been possible to ask patients for consent to collect this data, as some were too unwell to be approached. However after careful consideration the fact that the survey was undertaken principally as a service evaluation and was funded as such, fitted with Central Office of Research Ethics Committees (COREC) guidelines; furthermore the LREC gave approval to the study in this form. The findings have indeed been used directly in developing services for the community in which the study took place.

5.4.3 Data analysis

5.4.3.1 Review of analytical techniques employed

The analysis of these interviews followed an iterative process which began during the interview, since the text was not verbatim in its entirety, but emerged in part from my understanding of what the participant was saying. (I will discuss this aspect of the analysis in the Section 5.4.3.4 page 192). Nevertheless, the record of the interview is referred to as ‘the text’ (Miller and Crabtree, 1999).

As described in Section 5.4.2.3 (page 184) and illustrated in Figure 5-3 (page 185), the critical incident (the admission process) formed the unit of analysis into which all other analytical processes were linked. This enabled comparison across participants to be made as well as a chronological order to be established of events within the text for each participant. Analysis followed two schemata categorised by Miller and Crabtree as ‘Immersion/ Crystallization’ and ‘Editing’.

Immersion/ Crystallization has been defined as:

‘Cycles whereby the analyst immerses him – or herself into and experiences the text, emerging after concerned reflection with intuitive crystallization, until reportable interpretations are reached’ p180 (Borkan, 1999).

This process encourages intuition and creativity so that the researcher can ‘hear, see and feel the data’ p180 (ibid). Using this technique enables a movement of focus from the parts of the texts to the whole of the text, and a comparison between texts in a continuous and evolving manner. Reflexivity is an important aspect of this type of

analysis, since it is important that the results emerge from the text, rather than interpretation being imposed on it.

The editing style of analysis takes what might be seen as the opposite approach, moving from the text and applying codes inductively to it, allowing themes to emerge from the text. The term 'editing' therefore encompasses analytical schemes such as grounded theory and the constant comparative approach (Addison, 1999). This does not encourage a holistic view of the texts in the same way as immersion / crystallization, however, it is inherently more systematic, thus presenting a useful technique to 'check' the interpretation developed through the more intuitive approach.

Using these two techniques in an iterative way, enabled me to achieve a detailed analysis and I found it to be particularly suited to my own personal working style. The third method of qualitative analysis described by (Miller and Crabtree, 1999) is the template approach, where a code book or template is used to analyse texts. I used this technique for analysing data in the study presented in Chapter-6 – (HCA study) and will discuss this technique in Section 6.7.3 (page 256).

5.4.3.2 Details of the formal analytical schemes undertaken

Initially I read the text and made a basic empirical analysis of the route of admission for each patient, i.e. the chronological order was established. This enabled a map to be constructed summarising the various routes taken by patients (Figure 5-4 page 199).

For the second reading of the text I used the immersion technique, through which I sketched out a complex emerging picture using a mind mapping process onto several sheets of flip chart paper which were laid out on a large surface. By this technique I was able to gain a sense of interaction between various features of the critical incident. I used these charts again in the final phase analysis.

I undertook the third reading of texts using an editing technique in which I attached codes to fragments of text which I categorised according to emergent themes. This process utilized QSR NVIVO Version 1.2 software. I undertook this part of the analysis to allow a more intensive interaction with all segments of text so that no

issues would be overlooked and to allow a comparison of similar phenomena across texts.

Thus through these schemes, the themes which emerged enabled me to understand the factors associated with emergency admission of patients, the issues faced in the community by palliative care patients and the decision making process which led to contact with the professional or service which resulted in admission.

Once I had completed the analysis I wrote up the findings and these were read by my research supervisor. In addition I presented the findings at research meetings. These were an important aspect of the reflexive and validity testing process. My final write up of these interviews, which is presented in this chapter (Section 5.4.4) I undertook after the key informant interviews had been completed. Data from all three studies enabled me to undertake triangulation.

5.4.3.3 Testing the validity of data and analysis

Various methods have been described to ensure the validity of the findings in qualitative research. This includes checking the text with participants after completion of the interview, analysis by more than one researcher to check interpretation, challenging the interpretation by using other 'readings' of the text, looking for disconfirming examples in the texts and wide discussion of the texts and their interpretation with other researchers and practitioners. Key to ensuring validity in qualitative research is reflexivity which I describe in the next section. In addition, triangulation from other data sources and theoretical insights is used to test validity.

In this study, I searched for disconfirming examples in the analysis, to challenge the emerging insights. I used key informant interviews to reflect the findings with other locally based practitioners, so that their interpretations could be recorded and their insights could challenge my reading of the texts. Finally I conducted, audio recorded and analysed five further interviews from a critical incident case study (Appendix 2 page 314) using this data to check the texts of the original interviews and the initial write up of the analysis. Checking text with participants was not feasible and therefore not attempted.

5.4.3.4 Reflexive process

Undertaking this study challenged my previous scientific training which reinforced the concept of data collection by an 'objective' observer as the normative conditions for rigorous inquiry. Understanding that the researcher exerts an influence on and becomes part of the data was a challenging concept to learn in a deep sense. The reflexive approach which I developed is described in this section, although the learning process is inherently difficult to describe as it constitutes 'knowledge in action' p50 (Schon, 1991) – 'know how', rather than 'knowing about'. A useful analogy, also used by Schon is that of jazz musicians, whose improvisations cannot be reduced to a verbal description. I will discuss the concept of this type of knowledge in more detail in Chapter-7 (Section 7.4 page 296).

As a clinician I was experienced in interviewing patients in the course of my work. This type of interviewing aims to explore the patient's medical history and their ideas, concerns and expectations, to achieve a clinical diagnosis, to understand the patient's preferences for management and assess the effect of treatment (Mishler, 1984). This familiarity with interviewing patients afforded both advantages and disadvantages in this study. Firstly, it enabled me to select suitable patients for interview and secondly, I had experience in putting patients at ease and looking out for signs of fatigue or distress. Thirdly, it provided me with communication skills, including noticing verbal and non verbal cues and finally experience in interviewing, listening and taking notes simultaneously.

However, I was aware that my practice as a clinician was to reconstruct the patient's narrative into a *medical* history in a semi-automatic way, which involved tending to reduce the patient's explanations to clinical categories (Kleinman, 1988). It was necessary to learn a new method of listening to the participant's narrative, asking for clarification of statements rather than making assumptions as to the patient's meaning. This process was however complicated further by necessarily having to reduce the narrative to note form. The complexity of this process necessitated a continuous reflection on the interview technique throughout the study to ensure that a detailed description of the participants' narrative was produced. The most satisfactory method of conducting the interview and recording the data, I found, was to make extensive notes and to write down key phrases verbatim when these illustrated the participants' narrative during the interview. Following the interview I

immediately dictated a fuller version of my notes making sure that as much of the detail of the narrative was retained. I later transcribed the dictated file into a text document which I used for analysis.

Furthermore whilst analysing the texts after data collection was complete, it was important to continue to question the assumptions I made from my standpoint as a clinician. However, that standpoint also had advantages as I had a detailed understanding of the health care context in which the study was conducted and I also had access to the perspectives of health care professionals informally (i.e. outside of the research) to allow ongoing development of insights through a continued reflective and reflexive process. Thus I developed a dialectic process whereby the text challenged my assumptions whilst my prior knowledge and developing knowledge as a clinician-researcher aided in interpretation of the text. Hence the reflexive process involved a dual focus – ‘reflexivity “in” action’ whilst undertaking the interviews and ‘reflexivity “on” action’ during the process of analysis p178 (May, 2004).

5.4.4 Results

5.4.4.1 Introduction

Interviews with 30 patients and 7 relatives were obtained. In addition a number of discussions with health care professionals recorded in my field notes provided insights into the reasons for some patients being admitted. I will present the results in the next sections, following the schema of the emergency admission critical incident, i.e. problem faced leading to admission; the admission process - who was called; and finally contextual factors. A brief report of the results formed part of a book chapter (Worth and Munday, 2007).³

5.4.4.2 Problem faced leading to admission

All of the interviews established that the patient had a clinical problem. None of the admissions were for purely social reasons, i.e. the patient could no longer be cared for in the community. Whilst this was the case, it was apparent that some patients did have complex problems which included problems with coping at home or problems for their relatives in caring for them.

³ The numbering system used in Worth and Munday (2007) is different from that used here, both having been adapted from the original research participant identifiers employed.

Symptom Problems

Symptom problems particularly when severe led to the need for admission. These were sometimes single symptoms, particularly pain as illustrated in the case of a 54 year old lady with skeletal metastases from carcinoma of the breast, admitted from the oncology clinic for palliative radiotherapy because of pain in her hip which had been increasing over the previous week (Box 5-2, Patient 44).

Patient 44: The Monday before admission she went to see her GP as she was getting pain in her hip. This had been increasing over the last week. The GP prescribed painkillers and told her to come back in a week or sooner if the pain hadn't settled. The GP said that she would call [oncologist] to see if he could see her urgently in the clinic.

Patient 79: She had developed abdominal pain in the upper and lower abdomen yesterday. She has cancer of the ovary and the "liver pressing on the pancreas". Her bowels have been quite bad and she has been receiving medication for this. Yesterday she was vomiting "green vomit" in the evening. She had seen [oncologist] on Tuesday, the day before, but she was fine at that time. Her husband decided to telephone the GP emergency service.

Patient 65: "On Sunday night I stayed with my son. I had not felt well on Friday, Saturday and Sunday. At my son's my breathing became irregular. I had taken my nebulisers and my oxygen cylinder to my sons". She became more and more breathless overnight and did not get better with the oxygen or the nebulisers. "In the end I was gasping for breath and so my son phoned for the ambulance". (Woman with COPD)

Patient 22: He has lung cancer and had a partial pneumonectomy followed by radiotherapy nine months ago. On the morning of admission he asked his partner to call the ambulance as he was very breathless and was unable to move.

Patient 78: He has carers who come in twice a day who help him to climb up the stairs and occasionally wash him. His wife otherwise does all the caring as this is what she wants to do. When they tried to get him up at 9:30PM he was in a lot of pain and was unable to stand or walk. They called the paramedics who carried him on a chair up the stairs. The next morning he was just as bad and he could not walk. His wife called the GP who spoke to [oncologist] and arranged for admission.

Patient 35: He had chemotherapy three weeks ago and since that time has been suffering from haemoptysis which has been gradually increasing. On the morning of admission the GP was contacted by the district nurse to explain the increase in this haemoptysis and the GP arranged for him to be admitted to the EAU.

Patient 29: She had felt unwell the night before admission with nausea and fever. This was ten days following chemotherapy. She phoned the district nurse who said it was better if they contacted the ward as it was the weekend.

Box 5-2– Problems leading to admission – symptoms and disease complications

Nausea and vomiting was another common symptom leading to admission as illustrated by a 59 year old lady with carcinoma of the ovary in whom vomiting

associated with pain had occurred suddenly on the day of admission, only hours after she had seen the consultant oncologist in clinic (Box 5-2, Patient 79). Shortness of breath was frequently the precipitant for admission being the commonest trigger for patients with end stage cardio- respiratory disease, but also occurring in lung cancer. Breathlessness would often be of sudden onset and would frequently end in a call for an ambulance (Box 5-2, Patient 65, 22).

Complications of disease or treatment

Complications of malignant disease, such as spinal cord compression, haemoptysis and hypercalcaemia were sometimes the reason for admission (Box 5-2, Patient 78, 35 and Box 5-2b, Patient 11) whilst other problems such as deep vein thrombosis, commonly associated with cancer were also noted.

Other patients were admitted with complications from treatment. Several patients were admitted with neutropenia following palliative chemotherapy, as in the case of a 57 year old lady with breast cancer (Box 5-2, Patient 29). Patients receiving chemotherapy were given instructions to call the oncology ward if they became unwell during or in the days after their treatments, although at times the patient did contact primary health care professionals before telephoning the ward. Another patient was admitted because of difficulty swallowing following radiotherapy to the neck which led to dehydration.

Complex problems

The problems faced by patients were frequently multiple often forming a complex pattern of interaction, compounding each other until a trigger point for admission was reached, such as in the experience of an elderly patient admitted with lung cancer (Box 5-2a).

Another example of complex issues leading to admission is of a 49 year old patient with cancer, admitted to the radiotherapy wards where she was found to be hypercalcaemic (Box 5-2b). On the day of admission she phoned the oncology ward but they had not beds and advised her to call the GP. The GP visited, but did not admit her and she was not happy. Therefore she called the oncologist and spoke to his secretary. The oncologist managed to get her a bed on the oncology ward and she was admitted.

Patient 17: She looks after her brother who had lung cancer diagnosed just after she was diagnosed. He was admitted to hospital the day before she was. When she was having radiotherapy and was unable to eat "he used to get angry, but when he was diagnosed with lung cancer just after and was having chemotherapy and was not able to eat he said 'that was different'". She is the one who does the caring. "He says that he has done things but he has actually done nothing". She looks after his tablets and makes sure that he gets them at the right time. "Even then he won't take them". Caring for him has left her tired and depressed. There were a lot of problems between them when he became increasingly unwell and she wanted to go for extra help. He became very angry when she wanted to call for the district nurse to visit. Because she was caring she did not notice her own tummy swelling. When the district nurse visited her brother she said "I think you're in need of help too". The next day she phoned for the district nurse who came and gave her an enema. This was not effective so the district nurse went to see GP who came in to see her, and admitted her.

Box 5-2a

Patient 11: Her problems were that she was feeling increasingly weak, she has no appetite and couldn't be bothered to eat. She also could only get up and downstairs on her hands and knees. In the time since she had been unwell - over the last two weeks - her husband had to do increasing amounts at home. They live with her husband's teenage son and her own teenage daughter. She feels that her husband is left to do everything and children don't help. This makes her feel quite guilty as he has to do these things when he comes back from work. She feels guilty about not being able to do simple things such as reaching for the telephone from the bed and having to call him to get it for her. (When she was telling me this she became upset and cried). She said some days things were better than other days and she just couldn't tell how she was going to be. For instance on some days she had still been able to cook.

Box 5-2b

In both of these examples, physical problems – constipation, weakness and debility and hypercalcaemia - are compounded by social issues. In the first (Box 5-2a) the patient needs to act as carer for a sick and demanding brother even though she has advanced disease, and in the second (Box 5-2b), role reversal within the family occurs with the mother struggling and failing to fulfil her role. These problems lead to feelings of resentment for one and guilt for the other patient.

Sometimes carers were not able to cope with the level of care needed for patients with complex problems, even if community care was available, as in the account of a wife caring for her dying husband. The DN account recorded in field notes which accompany the carers narrative indicate that she saw the situation from a different although no less complex perspective (Box 5-2c, Patient 46).

Patient 46 (Account from Wife): He had been home for two weeks following diagnosis of hepatoma, for which he had been in hospital for six weeks. She looked after him herself for the first ten days but things were not easy. "The district nurses thought that they would help me by sending in the 24-hour nursing care but actually they gave me more work as they tended to spend time sitting around and I had to race around making cups of tea and things. I had no time to think. I had too many people around me. They were all running in and out and coming at different times. I would have carers coming in the morning and in the evening to wash him, but in between that was the problem. There were folk there all the time and I couldn't get a rest. A carer needs rest and comfort as well as the patient. Whilst he is in hospital I can go to do my shopping and my friends can take me back and forward, but at home in a small bungalow it is more difficult, there is not enough space. In hospital the nurses seem to know when to come in and when to go away and when to come back again."

DN account: His wife knew of the diagnosis but the patient did not. The wife did not want him to be told. This caused problems and for this reason the Macmillan nurse was not involved.

The patient had severe diarrhoea and the wife was having great difficulty in coping. Fast response (an intermediate care service) was involved with him. The next day he became semi-comatosed, his abdomen became distended and he was only passing small quantities of concentrated urine. They called the GP who told them to call 999 and get him back into hospital.

Box 5-2c

Crisis admission

On occasions problems reached a critical phase, so that a crisis was precipitated.

Whilst many situations required urgent admission some were more striking when the patient or relative identified the problem as needing immediate action and called for an ambulance or other immediate assistance. These situations were common for patients with COPD when they became severely breathless (Box 5-3, Patient 73); although even then the patient would sometimes wait to see if the situation rectified itself (Box 5-3, Patient 58). A similar crisis might also occur in patients with malignant disease, especially lung cancer (Box 5-3, Patient 47).

Crises where the patient collapsed before admission were uncommon, but could happen suddenly or unexpectedly (Box 5-3, Patient 74). Sudden and unexpected deterioration might lead to a terminally ill patient being admitted as happened with a 57 year old man with bladder cancer who had been previously well and driving his car three days before being found unconscious at home by the DN (Box 5-3, Patient 5). On admission renal failure was diagnosed and he died peacefully in hospital three days later.

Patient 73: Admitted at 10 o'clock on Saturday night. He had felt reasonably well during the day but went outside into the cold air and became acutely short of breath. He took his nebuliser and his home oxygen but these did not help. His son was with him and once they found that it had made no difference they called an ambulance this time. "I could not breathe at all. The ambulance came quite quickly".

Patient 58: He has a long history of emphysema with home oxygen. "I can normally feel it coming on. Sometimes it's a panic attack and 70 to 80 percent of the time I can handle it. I sit and relax and wait. If someone is with you that helps. At times it is so bad I cannot control it. My colour changes, I go grey and I have serious problems." "This time I was standing in the kitchen for about 4 hours holding onto the table. At about 5 PM I could take no more. My wife called the GP, but in the GP was not in. She was out seeing another patient. The receptionist told my wife to call for an ambulance and I also told her to dial 999. The ambulance came in about three minutes, they were very quick, they are always very quick. They measured my oxygen level in my blood by their machine, which was 60 to 74 percent and they said 'you need to go in'".

Patient 47 (Wife's Account): On Monday afternoon he was having difficulty because his mobility had become poor and even though his bed is downstairs he had difficulty getting to and from bed. On Tuesday morning his wife went out and when she came back he was very short of breath and getting rather panicky. She decided that she would not call for an ambulance and paramedic at that point but phoned the GP surgery for a home visit. "They all know about his problems at the surgery and I talked to one of the receptionists. The GP said to the receptionist that he would arrange to get him admitted". The GP organised the ambulance.

Patient 74: He always feels breathless and is on constant oxygen. He is only able to get to the toilet with help and get dressed with help from his wife. He was sitting on the toilet on Saturday afternoon when he collapsed. He does not know what happened. The first thing he knows is that he was lying on the ground. His neighbours had come over to help his wife. He might have been unconscious for around about five minutes.

Patient 5 (Field note - comment from DN): Two days before admission they thought he had developed a UTI. The GP had come out and prescribed trimethoprim the day before admission. However, on the morning of admission he was found to be poorly responsive, his urine output was very low and was just "very thick brown stuff". They telephoned the GP who told them to send him to hospital (i.e. call 999).

Box 5-3 - Examples of Crisis Admission

5.4.4.3 The admission process - who patients or their carers called

Table 5-7 (page 179) gives details of how the 81 patients identified in the survey were admitted to hospital. Much of this information was found in the hospital admission records completed in EAU which indicate whether the patient had been referred by a GP or had been admitted following an ambulance call. For patients admitted to the oncology ward, who bypassed the EAU, the information was obtained from the patient's record or from the ward staff. Through the interviews and from discussions with health care professionals it emerged that the process of

admission was often complex, involving several professionals and services. For instance for the patient discussed above who collapsed with renal failure (Box 5-3, Patient 5) the EAU admission sheet recorded a “self referred 999” admission, whereas the ambulance was called by the DN after she had been advised to do so by the GP. From the interviews it emerged that DNs were frequently involved in the admission process, although their role was largely invisible in hospital records. As a result of data available from all sources including patient interviews and discussions with HCPs, a map of routes of admission has been constructed (Figure 5-4), which emphasises the relative frequency of different routes to admission.

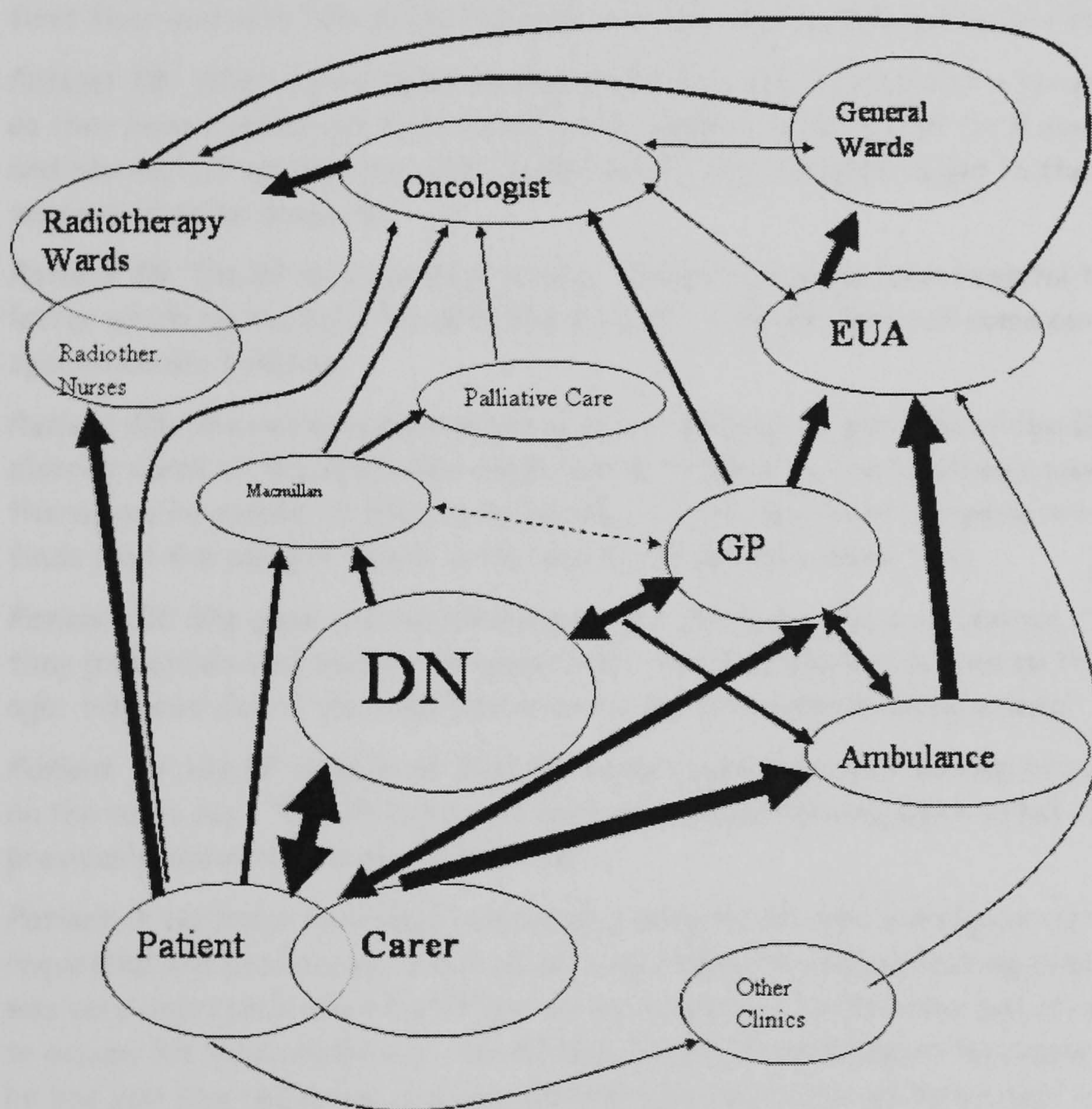


Figure 5-4 -Route Map of Admissions for Patients

The choices patients and their carers make concerning whom to call in which situation seems to be influenced by three overlapping and interacting factors. Firstly, they needed to have confidence in the professional involved, which was enhanced if the patient had an ongoing relationship with them. Secondly, they were aware which

services were available at which time and would alter their practice accordingly, and finally, they needed to have confidence that the appropriate outcome would be reached as a result of the action they took.

Patient 73: (patient with COPD) He has been in hospital twice in the last six months both for between five and 10 days. He has not seen his GP for about six months. He finds it difficult getting out of the house to see him although last time the GP did come to see him at home when he was called.

Patient 36: (patient with cancer) She has not seen her GP for about three months, when her GP paid a courtesy visit after the diagnosis of her cancer. She says "there has been no point in seeing my GP as I get my medication on repeat prescription". She goes on to say "not sure what the GP could do for me - in any case her surgery is on the first floor and with breathing like mine it is very difficult to get up the stairs"

Patient 58: When asked about seeing the GP he said "it is a bit of a struggle to see him as they have a policy not to do home visits, however I think that Dr X would come out and see me if I needed her. She is very good". He struggles to get to the doctor's surgery when he needs to.

Patient 38: The GP only comes if called. "When I go home from hospital they give me a letter which my husband takes to the surgery". The GP does not come out spontaneously however.

Patient 55: She reflected on how it is often difficult to get hold of the GP. If the district nurse or the Macmillan nurse wants to speak to him he always seems to be there, and he speaks to them very quickly. If she does need to speak to her GP she finds that she can get to him in the end but it can take some time.

Patient 32: She does call the GP surgery but she feels she is a nuisance. "When I call they [receptionists] ask lots of questions". She last saw her GP two or three months ago. He does visit if she asks him to or he sends a district nurse around.

Patient 74: His GP came in on Tuesday before admission and the district nurse came in on the same day. The GP came on a cold visit without having been called. He saw him previously about two weeks before that.

Patient 3: He has a very good relationship with his GP, who will always visit when requested and occasionally will visit without a specific request having been made. He was very impressed when his GP was asking him about his hobbies and encouraging him to occupy his time creatively. His GP spent some time looking at his watercolours which he has just started doing, and also photographs which he has taken over the years.

Box 5-4– Patients experiences of their GP

1) Professionals and services involved with the patient

Patients with both malignant and non malignant disease often had not seen their GP for several months, leading to them reflecting that the GP was rather distant with regard to their care (Box 5-4, Patient 73, 36). Most patients indicated that their GP would make a home visit, but this largely did not happen routinely and there might

be some reluctance by GPs to do this (Box 5-4, Patient 58, 38). Also it was sometimes difficult to get through to the GP for a telephone consultation (Box 5-4, Patient 55) and one 88 year old lady with COPD said she felt guilty about calling the surgery (Box 5-4, Patient 32). Conversely GPs occasional did visit without being called and this was appreciated by patients (Box 5-4, Patient 74, 3).

Patient 68a: "My GP is very good and keeps in touch by receiving reports from the hospital. I last saw him a month ago when I called him out as I was getting constipated. I asked him to give me something to help me go to the toilet." The GP only comes if called "but the district nurses call in, originally once every two week and now once a week and they will come more often if I need them to". They decide on the previous visits when the next visit will be.

Patient 41: "The district nurses will visit me when I go home if I let them know that I am home, they also keep in touch by sometimes dropping in."

Patient 55: The district nurse calls every other week if she is asked, and phones up every now and again to check on how she is.

Patient 36: She feels she is being well look after in the community, her district nurse was visiting every week but she asked her to visit only every other week as she felt so well.

Patient 68b: The district nurse had come out to him on the Tuesday and they had discussed how he felt. The DN said it would take longer for him to get things sorted out if he went through the GP as he was going to the day centre in the oncology unit the next day. "Obviously it did because I saw the district nurse on the Tuesday and was admitted on the Thursday which was very quick".

Patient 30: The district nurses were visiting twice a week and coming straight away at other times if called. As she had deteriorated the district nurses were visiting more regularly. On Sunday morning they came into see her spontaneously having visited the day before. They telephoned the doctor and an out of hours GP came to see her and suggested admission.

Patient 24: She has only seen a district nurse once when she was discharged last time about four weeks ago. She came to see her to help her sort out her medication which was very confusing. When she left she said "when are you going to see me again?" The district nurse however said she was too busy to visit. When her daughter said to her this morning that she would try to get the district nurse for her when she went home she said "I don't want to she was rude to me the last time".

Box 5-5 – Patients' relationship with DNs

In contrast DNs had much more frequent contact with patients, often taking a central role in monitoring the patient's condition. They would arrange to visit regularly (Box 5-5, Patient 68a, 41) sometimes negotiating the frequency with the patient or telephoning to find out how the patient was (Box 5-5, Patient 55, 36.) The district nurse was often therefore the professional who was first involved in assisting the

patient who had difficulties, either by the patient waiting for her appointed visit (Box 5-5, Patient 68b), or by the patient or carer calling for advice (Box 5-5, Patient 30).

When the DN was aware that there were problems some would pay a follow up visit to check on progress. In this way they were frequently the ones who were involved in initiating the admission process, often by contacting the GP to ask for advice (Box 5-5, Patient 30; Box 5-3, Patient 5). Whilst most patients were very satisfied with the input from DNs, one patient with COPD was not happy because the DN was not prepared to visit regularly (Box 5-5, Patient 24).

Some cancer patients had regular contact with Macmillan nurses who they were able to contact directly. In this way Macmillan nurses were occasionally involved in organising admission when necessary, particularly through discussion with an oncologist (Box 5-6, Patient 42, 63). The Macmillan nurse would sometimes contact patients directly to find out how they were, such as happened with a cancer patient who was admitted with suspected spinal cord compression (Box 5-6, Patient 69a).

However not all patients felt that it was necessary to have a Macmillan nurse. One patient felt that they were overworked having witnessed the care given to his own mother. Another was happy with the care being provided by the DN, feeling that having a Macmillan nurse would indicate a failure of personal goals (Box 5-6, Patient 79) and a third patient was aware of the drawbacks of having too many professional involved. However, along with several others this patient expressed great satisfaction with the personal service he received from the oncology ward, which was always available (Box 5-6, Patient 35). Others compared the oncology ward favourably with the general hospital (Box 5-6, Patient 69b).

2) The service or professional who the patient judged as being available

Perceived availability of a service or health care professional was an important factor in determining who patients or their carers would call in an emergency. If it was considered that a service might be slow in responding an alternative option would be sought.

District nurses as well as visiting regularly and maintaining a relationship with the patients were accessible at weekends and could maintain continuity for patients at that time (Box 5-5, Patient 30).

Patient 42: Monday morning his wife decided to call the Macmillan nurse and she phoned herself. The Macmillan nurse spoke to the GP and to the Oncologist who brought him in to the oncology ward.

Patient 63 (From discussion with Macmillan nurse in field notes): The patient had suspected spinal cord compression. The DNs noted that the patient had a limp in her right leg which had started some days before. The district nurse phoned the Macmillan nurse on Monday to say that the limp had worsened. They had been holding on as she had an appointment with Clinical Oncologist the next day and they thought that her problems could be investigated further at that time. As a result of the telephone call from the DNs on Monday morning the Macmillan nurse spoke to the oncologist and he arranged an urgent admission.

Patient 69a: She had noticed over the previous week a numbness in her bottom and down her right leg. She had also been a little unsteady on her feet. She had been in clinic with the oncologist on Monday afternoon, the day before admission and had told him about her symptoms but he did not seem to have registered it. The next day the Macmillan nurse called to find out how she had got along with the oncologist. She told her that he hadn't said anything about the symptoms. The Macmillan nurse therefore phoned the oncologist who phoned the patient back and told her to get on her bag packed, as he was bringing her into hospital.

Patient 79: She said "everyone is different and copes in their own way, if I had seen a Macmillan nurse it would have meant that I was not coping on my own with it. It is just me and the way that I want to do it." She has every confidence in her own GP, the oncologist and the DNs.

Patient 35: He has not had any contact with a Macmillan nurses although the district nurse has asked him if he would like to. He is aware that having someone else coming in may lead to conflict and he is quite happy with the care that he is receiving from the district nurses at present. He said to them "I will talk to a Macmillan nurse if you would like me to but I am happy with the care that you are giving." He has not seen his GP since the day that he was diagnosed as having lung cancer as he says "I was whisked into the [city's] cancer care system which does things at such a pace that I have not needed to see anybody else". He "cannot praise the oncology ward highly enough". He says that "you can telephone them day or night for advice and they are always ready to help and are very pleasant".

Patient 69b: She is very pleased with the care which she receives on the oncology ward, she says "it's like a hotel here". She compares it very favourably with the general hospital which is so big with fewer benefits; such as you have to order your meals a day before whereas in the radiotherapy ward you get a choice at the time.

Box 5-6– Patient experience of specialist services

Patient 29: They have waited up to 4 hours for a GP to call at the weekend and think it is a waste of time to call them. "The GPs ask you to tell them your history from the beginning and then they tell you to go to hospital anyway."

She thinks it is very good that the oncology ward is contactable 24 hours a day, but the problem arises when there are no beds on the oncology ward. She then has to go to the general hospital which she describes as "hell on earth".

Patient 1: When he [a 72 year old man with COPD] called the ambulance last year the crew told him that in a similar situation in the future he should call them directly rather than anyone else, "because we are the only ones who can help you".

Patient 12: She [60 year old lady with COPD] was advised by somebody - she thinks at the hospital - to call an ambulance rather than GP if she needs to come in. She feels that the GP takes too long to come, it might be several hours.

Patient 37: She was discharged four days before her readmission this time, as they wanted to take her home for a break. However having been at home for four days she was in such pain that she asked her daughter to take her back to oncology. Her husband phoned the oncology ward to tell them that she was on the way back in her daughter's car.

Patient 54: She [relative, an oncology nurse] went out to visit him because she'd heard that he was not very well. When she saw his condition she decided that he ought to be admitted. She phoned the ward to find out if there was a bed and as there was she arranged for him to be admitted, taking him there in her car.

Patient 3: On the day of admission, a Saturday afternoon, he telephoned the co-operative for a visit. Despite describing his condition to them, the doctor asked him to come down to the centre. The doctor told him that he did not have any equipment to examine him adequately at home and if he did not come to the centre then he would need to go straight into hospital. The doctor sent a car with oxygen and the patient struggled to get into the car. At the centre he had to walk about 20 yards from the car into the waiting room. Having arrived there he was admitted immediately to the EAU. He feels it was inappropriate to be asked to come to the centre in his condition.

Box 5-7– The availability of services used leading to admission

This contrasted with GPs who were often seen as being less accessible, especially out of hours. Lack of personal knowledge of the patient could lead to reluctance to call the out of hours GP (Box 5-7, Patient 29). This patient at a weekend had therefore called the DN for advice who in turn advised her to call the oncology ward directly. She was relieved to find on calling the ward that beds were available as she was concerned about being admitted to the general hospital – an experience she described in graphic terms.

Patients with non-malignant diagnoses, had two possible routes to admission, one via the GP, but the more common route into hospital seemed to be through the ambulance service with the patient or carer dialling 999. Some patients did contrast

the rapid response of the ambulance service with the slowness of response from general practitioners (Box 5-3, Patient 58). The practice of calling for an ambulance to enable immediate admission was also reinforced by health professionals, including ambulance crews and hospital staff (Box 5-7, Patient 1, 12). Also calling for an ambulance could be reinforced by the practice of primary care teams or GPs, who summoned ambulances on the basis of the patient's history rather than seeing the patient (Box 5-3, Patient 58, 47).

Clearly situations exist in which a call for an ambulance for immediate admission is entirely appropriate, for example in cases of unexpected collapse (Box 5-3, Patient 74) or severe central chest pain, since delay in admission and treatment may affect outcome adversely. It might also be difficult for a GP to visit a patient promptly because of surgery commitments. However, it is possible that lack of clinical assessment may lead to the admission of patients who could have been clinically managed at home. Therefore it could be argued that for palliative care patients prompt attention from a medical practitioner in the community should be the norm.

There were also less conventional ways of obtaining help available to patients and their carers. One husband whose wife had recently been discharged from the oncology ward was so concerned about her condition that he asked his daughter to take her back to the ward in her car (Box 5-7, Patient 37). Similarly, a senior oncology nurse visited a relative herself and decided that he needed to be admitted to the ward, transporting him there in her car (Box 5-7, Patient 54).

However, patients might go to some length to access services if they thought that they could *avoid* admission. One patient with cor pulmonale described how he was admitted having struggled to visit the out of hours centre after a home visit was refused; he had attended in order to try to avoid inevitable hospital admission which would have resulted from calling for an ambulance (Box 5-7, Patient 3).

3. The professional or service in whom the patient felt confidence to deal with the particular situation effectively

At least two services were available to all patients in an emergency situation: their general practitioner or out of hours GP services and the ambulance service. Many also had access to district nurses and patients with malignant disease had other options including telephoning directly to the oncology ward. The availability of the

oncology ward, the personal nature of the care and the perceived skill and dedication of the oncology staff were important factors in fostering confidence in patients who had received this service (Box 5-8, Patient 42).

Patient 42: When I asked him whether he had care from anybody else he answered "who else is there? I am getting care from the top", which I clarified as meaning the consultant oncologist.

Patient 1: He thinks when he is very breathless it is always better to call the ambulance rather than the GP, because "he will only give you a couple of pills and leave you at home".

Patient 24: She was admitted with worsening shortness of breath from known COPD. She lives with daughter who has diabetes and osteoarthritis. She saw her GP one week before admission he gave her the option of coming into hospital. On the day of admission her daughter went to see the GP to tell him that her mother was worse. He arranged admission and gave a letter to the daughter but did not see the patient himself.

Patient 12: She says that she feels safer in hospital. When asked why, she said "because when I am bad they are there". However, she acknowledged that she was very frightened especially as she saw someone on one of the wards dying with her condition.

Occasionally she has been sent home from EAU after calling being taken in by the ambulance but she feels more confident with this than with seeing her GP when she feels very ill.

Patient 58: "It is so chaotic when you are admitted, and they really need to sort it out down in EAU. I know that it is not the hospital's fault but sometimes you remain there for 10 hours". "This time they got me up quickly in about three hours. Often I'm not admitted onto the proper ward and I am moved around chopping and changing. This is very difficult. I was on [the receiving ward] and I got no peace. It was only when I was transferred yesterday that I started to feel better and got a bit of peace". "This time when I got to the emergency admissions unit I was put onto oxygen. I was only down there for 3 hours but I felt very uncomfortable. I felt a lot worse while I was down there compared to when I was at home. They checked my blood gases and put me on steroids and antibiotics through a drip".

Box 5-8– Confidence in dealing with the problem

The likelihood of an acceptable outcome was also weighed up by the patient in making a choice about who was appropriate to call, in addition to the perceived availability of the professional or service. Some COPD patients actively sought to come into hospital, because they saw it as a place of safety and a place that could appropriately manage their condition (Box 5-8, patient 1, 24). One patient expressed how she would prefer to be checked out at EAU even if it meant being sent home again (Box 5-8, Patient 12). However, some patients with COPD felt they had little

choice and needed admission when they became very breathless, having to contend with the unpleasant process (Box 5-8, Patient 58; Box 5-7, Patient 3).

Cancer patients on chemotherapy were encouraged by the oncologists to contact the oncology ward if they had problems because of concerns about neutropenia, but patients could self refer themselves to the ward for admission if they had more general issues (Box 5-2b, Patient 11).

The senior nurse who had admitted her own relative (Box 5-7 Patient 54) explained why she had felt this to be the best course of action (Box 5-8a).

Patient 54: (Account of relative - senior nurse) She had not discussed the patient with the GP or anybody else, she feels that she would have done exactly as she had done if she had been on the ward and had been phoned by a patient asking for admission.

She feels that if anybody else had tried to get him into hospital he would have refused to come in. She told him that she would stay with him until he had been 'clerked in' and had had drips inserted etc. She thinks that if the GP had seen him he would probably have had admitted him to the EAU rather than directly onto the oncology ward. She wasn't aware of when the GP had last seen him.

Box 5-8a

5.4.4.4 Contextual issues

Many contextual issues have been discussed in the accounts of the problems faced by patients and their carers and the actions they take which lead to admission. In summary, for many cancer patients, the DN is central to their care and they rely on being followed up and monitored regularly by the DN with whom they have developed a trusting relationship. Many cancer patients also received care from Macmillan nurses, although some did not feel they needed a Macmillan nurse or felt ambivalent towards having one. GPs did feature in patient and carer narratives, but they tended to be more remote and less likely to visit unless specifically called and then at times only reluctantly. Conversely other patients recounted that their GPs did visit spontaneously.

Patient 73: He has been housebound and has not been out for about a year. He does get breathless if he goes out into the cold particularly. He is able to do things for himself such as go to the toilet and get dressed but he does get breathless doing it. His wife has just had an operation for a tumour and will be unwell and unable to look after him for about three months. He is not quite sure how they are going to cope and thinks that they might need to have carers although this has not been suggested so far. There are district nurses who call to see his wife but not for himself.

Patient 25: They have carers in three times a day from [a local nursing agency] and a Marie Curie night sitter 2 times a week. The GP will come in as needed and the district nurses visit twice a week principally to monitor her diabetes.

Patient 3: If he is very breathless he can call on the district nurse who will organise the "rapid response" team to place somebody with him. They will place a sitter with him who will stay 24 hours a day for up to 72 hours. Unfortunately if he needs care for longer than one week he would need to be admitted to hospital. He feels that "rapid response" are getting fed up with him.

Patient 58: I do manage to get around normally I can still drive my car and I carry oxygen in the boot and I have a wheelchair". "I won't be able to drive that for several weeks as I don't feel well enough". He has no visits from district nurses and he has no other help. His wife looks after him, in fact they look after each other, as she has a bad back. He cannot get upstairs to the bathroom even though oxygen has been pumped up there from his concentrator. He has actually only been up there twice but it was so difficult that he has not been out again.

Patient 32: She lives alone with her husband who is 90 and reasonably fit and able to do the shopping etc. She tries to do the cooking and manages to do some most days. This is the one thing which she identifies as being the major problem. They have carers to come in three times a week for 2 hours each time that they have to pay for. The district nurse does not visit regularly and did not visit when she was sent home from hospital last time.

Box 5-9– Contextual issues

However, patients with non malignant diseases were less likely to have DN involvement in their care on a regular basis. This may be related to the fact that DNs are increasingly only involved in task based activities, such as wound care, setting up syringe drivers etc. Patients with non malignant diseases are probably less likely to need specific nursing tasks to be performed than cancer patients and therefore less likely to have district nurses "checking up" to make sure all is well (see account of COPD CNS Section 5.5.3.4 page 221). The DN visited the home of one patient with severe COPD because his wife had cancer and not specifically to see him (Box 5-9, Patient 73).

Other services provided by a variety of carers were received by some patients including Marie Curie nurses and carers from other organisations, as described by the

mother of a young woman who had a brain tumour with long standing care needs (Box 5-9, Patient 25). Some patients could receive such services for long periods. One cancer patient had been receiving a 24 hour nursing package for three months, according to the DN who was responsible for his care. However, a non cancer patient explained that the 24 hour home care he could receive was limited to one week (Box 5-9, Patient 3).

Having carers in the home could be stressful, illustrated by a carer who expressed the preference for her husband being in hospital because “there were folk there [at home] all the time and I couldn't get a rest” (Box 5-2c - gives full extract). Nevertheless, few patients described having carers in the home, with most of the caring role for dependent patients falling to their relatives.

Many patients lived with relatives who were also elderly or unwell, managing as best they could with little help from community carers, such as a 62 year old man with COPD (Box 5-9, Patient 58). Whilst an 88 year old woman with COPD relied on her 90 year old husband as her main carer, with little other help, their son living 150 miles away (Box 5-9, Patient 32).

When patients were asked about services which they received in the community, several spoke about care received from social services or that they were awaiting housing adaptations. Many of the comments conveyed frustration at lack of availability (Box 5-10, Patient 18); the poor quality of care experienced previously, which made a patient reluctant to access social service help for herself (Box 5-10, Patient 69); or bureaucracy involved in receiving care benefits (Box 5-10, Patient 46). Adaptations to enable patients to cope at home could happen very slowly (Box 5-10, Patient 58) with one patient suggesting with a sense of black irony that he might not live to see the benefit of the work promised (Box 5-10, Patient 1).

Other patients did receive care from the social services department and did not complain about these issues, suggesting that expectations may vary between patients, however, no patients praised these services in the way that they did clinical services, especially those delivered by the district nurse and the oncology ward.

Patient 18: Her husband has been doing all the house work for the last three years including cooking, shopping and ironing. Sometimes she is able to help a little bit with washing-up and washing. Now however her husband needs help. They have been phoning around to try and get help themselves but have had nothing offered. She says "things are not like they were before with social services".

Patient 69: She paid for all her husband's care out of her own pension and the social services did not seem to be interested. The carer spent hardly any time with her husband. She used to bath him as quickly as she could and if she had gone out whilst the carer was there by the time she came back the carer would have gone even if she had only gone over the road to get a newspaper. In the end she cancelled the carer and did all the caring herself.

Patient 46: "The council social worker came to arrange funding but we couldn't get it because my husband could not sign the card. I was asked to go to the DHSS to sort it out. Whilst I was standing in this queue I said 'I cannot cope with that today', so I left".

Patient 58: He asked if he could have a shower put in downstairs and the council agreed to it. They sent surveyors around who said that it could be done. However in the end he was sent a letter to say that it would be three years until it was installed.

Patient 1: His wife has angina and finds it difficult to go up the stairs. In April they requested a stairlift and were told that they would not be assessed until August. He feels that it will then be another year until he gets a stairlift installed "and then I won't need it any more!" He feels that generally there is too much red tape associated with the social services; it takes three men to do the job of one man. He feels if there was less bureaucracy that it would be easier for people like him.

Box 5-10- Concerns regarding social service provision

5.4.5 Discussion

5.4.5.1 Limitations to the study

This study has several limitations so caution is needed in interpreting the results. I was unable to audio record the interviews which inevitably will have led to information, some of it potentially important, being omitted from the record. In addition it would have been particularly valuable to have had recordings of interviews to assist in the reflexive process, to check for leading questions or aspects of the interviewee's narrative which I missed, especially as I was a novice researcher. Further, since many patients, whilst keen to recount their story were easily fatigued, I was not able to explore some issues in depth or to prompt them for clarification, to the extent that I have been able to in later studies, neither was it possible to return to the patient to check my record of the interview. These issues will have a potential impact on the validity of the results.

Whilst care must be taken in interpreting the data, this is the largest study in the UK to have examined in depth the experience of palliative care patients admitted as emergencies to hospital beds. Some of the patients interviewed deteriorated following admission and died whilst in hospital, some within a few days of the interview. For this reason, some of the insights offered from this study are unique and therefore arguably a valuable contribution to the literature on palliative care. In addition they have enabled service development within the city in which the research was undertaken.

5.4.5.2 Discussion of findings

This study has examined in depth the reasons for admission of palliative care patients in terms of the experiences of patients and their carers in the community, the trigger to the admission and the action taken in seeking help from health care professionals or services. The interviews with patients and their carers and the discussion with health care professionals which I was able to record, enabled the complex processes leading to admission to be mapped out in much greater detail than was available from the patients' admission records.

The problems faced are frequently complex involving a range of factors including: physical symptoms, functional impairment, emotional and psychological distress, social isolation, debilitated carers and patchy services; all contributing to the precarious day to day existence with which patients contend. At times admission occurs when these issues reach a pitch where the patient and carer can no longer cope at home, at other times a crisis occurs such as worsening symptoms or complications of disease and treatment. Despite the conjecture that patients are admitted to hospital to die (Thorpe, 1993), there was no clear evidence that this happened frequently. Only one of the patients identified in the survey died in EAU and the reasons for this admission could not be explored. However, whilst some patients did die during that admission, frequently it was unclear that this would be the outcome from the information available at the time. Conversely, some patients who I did not interview because they seemed to be dying improved, were discharged and remained alive at the end of the study period.

Patients face a range of choices in seeking help including calling a GP or an ambulance, which is open to all patients, whilst other patients particularly those with

cancer are also able access other services including the DN, Macmillan nurse or oncology ward. Other patients will wait for a scheduled visit, especially those receiving DN or Macmillan nurse services. Even in a crisis patients may wait to see if the symptoms settle before calling for help. This results from a combination of reluctance to be admitted and altruistic concerns not to bother busy professionals especially out of hours.

Whilst some patients had poor experience of the admissions process, especially when they needed to go through the EAU or into the general hospital, no patient questioned whether hospital admission had been justified or not. Some patients had had previous contact with the hospice, though no patients cited lack of hospice beds as an immediate reason for admission.

Whilst hospital admission, is officially recorded as via a 999 call or as a GP referral, it is clear that admissions frequently involve much more complex processes. The two groups of professionals principally involved in the admissions process, apart from GPs and the ambulance service are DNs and oncology ward nurses. Although discussions with representatives from both of these groups were recorded in my field notes, I decided to interview them formally along with other key informants so that I could explore their experiences in more depth.

5.5 Key informant interviews

The key informant interviews undertaken are given in Table 5-11.

Lung Cancer Clinical Nurse Specialist
COPD Clinical Nurse Specialist
Oncology ward nurses x 6
District nurses 3 group interviews

Table 5-11 Key informant interviews

The interviews with the DNs, oncology ward nurses and lung cancer clinical nurse specialist (CNS) were data driven (Gilchrist and Williams, 1999), i.e. these groups were chosen because they were the key professionals involved in care of patients in the community or involved in patient admission as determined from the patient interviews (although the lung cancer CNS had only featured in one interview). The COPD nurse was not featured, but since this was a new post in the city and COPD patients were an important group of patients identified she was interviewed. It was judged that these professionals would provide insights into the data to corroborate

and legitimate the findings. In addition they would enable a deeper understanding of the context, structures and inter-professional relationships, including relationships of power which were fundamental to constructing a realist account of the issues surrounding hospital admission (see Section 5.5.4.1 page 224).

GPs and Macmillan nurses were not interviewed formally as key informants; however my insights from meetings with these groups in the period following the completion of the study were recorded in field notes. I did not interview Macmillan nurses formally because my close working relationship with them would have made conducting and interpreting such interviews problematic. Insights from Macmillan nurses have emerged through team discussions, including discussions following presentation of the results of the study to them. They have also become research collaborators with me on later projects, linked to this study, as described in Chapter-6 and Appendix-2 (page 314). Interviews with GPs were judged problematic and potentially difficult to achieve. By the time I was in a position to conduct interviews with GPs I had been appointed as consultant in palliative medicine within the PCT and this may well have influenced the interviews, with GPs possibly reluctant to reveal their practices and opinions to me. It has also proved difficult to achieve the agreement of GPs for interview in a feasibility study exploring provision of unscheduled care to community palliative care patients whether they were approached by a non-clinical researcher or a Macmillan nurse (described in Appendix-2). Some insights into GP attitudes however were achieved through meetings which I had with various GPs and an educational afternoon during which the views and attitudes of GPs towards community palliative care were noted by group facilitators who later recounted their insights to me.

5.5.1 Key informant groups interviews with DNs

Rather than interview DNs individually I decided to interview them as groups within the three localities within the city. This approach enabled insights to emerge through their interaction together. Whilst working from common offices, DNs work within three to four teams per locality with individual DNs working with different GP practices, giving a range of experience within locality teams. In addition DNs deal with complex issues in the community and my previous clinical work with them had revealed that there was a range of approaches to their work. Group interviews

enabled the commonality and the divergence in DN experience and practice to emerge and allowed discursive reflection on the findings from the critical incident interviews (Kitzinger, 1995).

These groups were held at a DN base within each locality over a lunch time and sandwiches were provided. The interviews were arranged through the three district nursing locality managers who gave an open invitation for up to 9 DNs per group to attend, encouraging representatives from each of the locality bases to take part. In the three groups five, six and seven DNs took part respectively (i.e.18 DNs) ranging from D to G grade with a range of experience from a few months as a DN to over 27 years (see Table 5-12). The groups were audio recorded and transcribed and field notes were also taken during the course of the interview.

Location	Grades of DN group participants
A	4G, 2E, 1D
B	2G, 2E, 2D, 1 Student nurse (observer)
C	1G, 1E, 3D

Table 5-12 - Composition of DN group interviews

A drawback of the group interviews was the lack of a second facilitator to enable notes to be made regarding interaction between the DNs. However, since these were key informant interviews to explore experiences of DNs caring for patients with terminal illnesses, the context of care, social structures and relationships between DNs and other professional groups, recording the interaction between members of the group was not a primary aim of the group. However, since interaction does affect the content of the discussion, I attempted to be aware of this. It was especially important for me to encourage the less vocal members to participate especially in groups where some members dominated, whilst recognising that nurses with greater experience could have more to contribute.

Relations of power will always affect the outcome of group interviews leading to inhibition amongst some members. Since the DNs were known to each other, there were likely to be pre-existing issues of power in the groups. At the time I was a specialist registrar in palliative medicine, known to some of the DNs so there may have been power issues between me and the groups, although one strength of the group was that the DNs could give each other support. It is perhaps inevitable that any DNs who were not comfortable with the process would have chosen not to

attend. Also it is likely that DNs with an interest in palliative care were over represented. However, it was apparent that not all the DNs considered themselves to be particularly skilled in palliative care, although palliative care is identified as a core DN activity.

Since these were relatively homogeneous groups, the possible emergence of 'groupthink', where assumptions or similar views could remain unexamined or unchallenged (Robson, 2002) was an important consideration. However, a degree of heterogeneity was achieved through DNs within the same group being from different teams, working with different practices and being of varying grades and experience. In addition the three separate groups with differing composition in terms of grading and experience enabled comparison between groups to be made.

5.5.2 Key informant interviews with oncology ward nurses and 'non-palliative care' CNSs

Oncology nurses have an important role in admitting palliative care patients and in giving advice to patients or carers who call. The nurse in charge of the ward on any shift could admit any patient who was registered under the care of a clinical oncologist and whom she judged merited admission. Oncology ward nurses fulfilled an important gate-keeping role for admission since many admissions were as a result of self referral of patients rather than coming from a community health care professional.

Interviews with oncology ward nurses who could admit patients were undertaken individually in the office on the oncology ward. I had reasoned that since these nurses work together on one ward they would form a very homogeneous group where 'group think' would be probably more likely than with DNs. The interview with the COPD CNS was conducted face to face in her office whilst that with the lung cancer CNS was conducted over the telephone.

Being known to the lung cancer CNS and some of the oncology ward nurses from my clinical work in the hospital might have affected these interviews. My strategy was to underline the fact that I was a novice researcher and their cooperation would be very helpful to me and they all seemed enthusiastic about the project. Only one ward nurse seemed nervous and needed reassurance, the others were confident and

seemingly direct both in their approach and their comments. There seemed to be no difference between the COPD nurse's approach to me and the nurses' whom I knew.

5.5.2.1 Data recording and analysis

All of the face to face interviews and group interviews were audio recorded and transcribed verbatim. The one telephone interview was recorded in note form during the process of the interview.

I checked all of the transcripts for accuracy and I listened to the group interview recordings on several occasions to re-examine the nuances of interaction. The transcripts of all interviews were re-read several times using an emersion technique with notes being made. Interviews were then coded and themes were recorded as they emerged using a constant comparative method across the interviews with each professional group. Themes emerging were then compared across professional grouping and I noted where common emergent themes were particularly strong or where difference arose.

I used the results from the analysis of the key informant interviews in the triangulation process to aid the interpretation of the patient narratives and to enable an understanding of the structural issues and interprofessional relationships which affect patient experience.

5.5.3 Results

5.5.3.1 DN group interviews – DN, GPs and Macmillan nurse roles

All of the DN groups saw themselves as being central to the care of palliative patients in the community, as initiators and co-ordinators of care, providing continuity of care and acting as the patient's advocate. Many underlined the importance of building up a relationship with the patient over time and ensuring that they did not let patients down, for example by always visiting when they indicated that they would.

Referrals to the DNs came mainly from GPs and hospital wards, especially the oncology ward, which had a policy of referring patients to DNs on discharge. Not all GPs would refer patients as early as the DNs felt was necessary, with some DNs indicating that nearly all of their referrals came from the hospital and GPs rarely referred.

All DNs stressed the importance of team working between GPs, DNs and Macmillan nurses. In each group there was a lot of discussion about the differences between GPs and practices in terms of how they worked with DNs. DNs indicated a spectrum of attitudes and practices amongst GPs with at one end those who would visit patients at the DNs request and follow patients up without prompting or with only a brief reminder. It was with these GPs that DNs indicated that they had a good working relationship. At the other end were GPs who would never visit willingly.

One DN indicated that she had twice needed to call an ambulance to take a patient to EAU so that a medical assessment could be done as the GP refused to visit. Another DN recounted how on several occasions a particular GP told her that he would not visit, but then she would find out that he had visited. Several DNs confirmed that when they had assessed a patient and telephoned the GP for advice, the GP might suggest that they call an ambulance to admit the patient. This was acceptable to them if they felt that the patient should be admitted, but frustrated them if they wanted to keep the patient at home.

Many DNs described strategies which they used to facilitate working with GPs on behalf of palliative patients. These included: getting to know the GP and the best time to contact him, having all the facts ready before approaching the GP and getting the Macmillan nurse to speak to the GP. This latter strategy could be problematic as some DNs felt that GPs were threatened by Macmillan nurses, which on reflection they thought may have been related to discomfort at the level of knowledge of Macmillan nurses.

DNs described very close working relationships with Macmillan nurses. Two groups mentioned how the role of the Macmillan nurse had changed making them less likely to be personally involved with patients than before, but they had become more knowledgeable about symptom control. They felt supported by the Macmillan nurses as they were always on the end of the phone; they could give advice and come to see patients when the DN felt out of her depth, and were able to speak to GPs about management.

Not all views on Macmillan nurses were as positive. One DN was very clear that she resented being the Macmillan nurses' 'handmaiden', particularly with having to institute the Macmillan nurse's instructions regarding setting up syringe drivers. This

would often occur at the end of the day and involved collecting medication from the pharmacy as well as setting up the driver. Finding a pharmacy with the drugs in stock could be problematic. Other DNs in the group recognised the scenario, but seemed more sanguine concerning this issue. Another senior DN expressed frustration at the high profile nature of cancer charities such as Macmillan and the local hospice and felt that district nursing was devalued; for instance they rarely received donations, although if they did they could buy equipment. At times they had provided most of the care in the patient's terminal phase yet a donation had been made to the hospice or Macmillan. Some patient's were reported to confuse the DNs with the Macmillan nurses.

One bank holiday it was a patient who was discharged before the bank holiday, and he was a very poorly man with advanced CA - his larynx, he was also an alcoholic and lived in a very deprived situation, a very difficult family situation, but he wanted to come home. He was sent home on oramorph, which he was able to swallow, but as the weekend progressed into the bank holiday he swallowed with more and more difficulty. In my opinion his symptoms, his pain, wasn't controlled, he was restless and agitated and in a lot of discomfort.

I felt that we needed to look at other alternatives for his pain control because he wasn't swallowing, and I called the doctor out, and together we decided that maybe fentanyl might be the solution - try to get as much oramorph into him as possible, but to start on a fentanyl patch. The doctor on the phone wanted me to put him straight on to a 50 microgram patch, I questioned that, saying that I didn't feel it was appropriate, and we should really start on a 25 microgram patch, and he said "Who do you think you are? Telling me, are you a Macmillan nurse?", and I said "No, I'm not a Macmillan nurse, I'm a district nurse, but I know that we should be starting this patient on the 25 microgramme to begin with, and reassess the situation continuously.". He didn't come out to see the patient, he asked me to go down and pick the prescription up from the [out of hours] office.

I went and picked the prescription up, it was written incorrectly, the doctor wasn't in the building anymore, so I had to wait for another doctor to come in to write the prescription correctly, then I had to find a pharmacist that was open, collect the prescription, then go back to the patient. He hadn't been seen during this time. It was very difficult - it's not how it should've been. In the end everything settled down, and I managed to get his symptoms controlled, and he passed away over the next few days peacefully and pain-free. But it was hard work.....hard, and it shouldn't have been.

G Grade DN - Group C

Box 5-11- DN Out of hours narrative

The time when DNs felt most isolated in their work was at weekends when they relied on the out-of-hours medical service which meant working with unfamiliar GPs (see Box 5-11) and when they felt the issues of not being able to secure a home visit

were heightened. The lack of Macmillan nurses at weekends and bank holidays was cited by all DN groups as being problematic which compounded the problems presented by the out-of-hours GP service. At this time if specialist advice was needed they sought it from the nurses on the oncology ward or from the hospice.

5.5.3.2 Oncology ward nurse perceptions

The oncology ward nurses were also aware of the problem with lack of specialist support for DNs out of hours and along with DNs suggested that Macmillan nurses working at weekends would be a valuable service. Most of their contact with DNs was when a DN phoned for advice regarding a patient, although frequently the patient for whom advice had been sought was subsequently admitted. The majority of admissions resulted from patient self referral, or referrals from Macmillan nurses or GPs.

Some nurses reported that patients who were known to them would phone up for advice about calling the DN or GP seeking reassurance that it was permissible to do so. Sometimes however, the patient called oncology for advice having been told to do this by the GP. One nurse was concerned that some GPs seemed keener to admit than to visit the patient and might phone up without having seen the patient. She reflected that this might be due to high workload for GPs.

Whilst the admission service was principally for chemotherapy related neutropenia, other oncological emergencies were commonly admitted including spinal cord compression, bowel obstruction, pain and nausea and vomiting. Several nurses spoke of the complexity of the issues involved, where general debility and a family struggling to cope defined the context of the problem leading to admission.

Constipation was another common problem needing admission, a feeling corroborated by one G grade DN who felt that this was the commonest reason in her experience for admission. In this situation when enemas had failed, if the GP declined a visit to perform a rectal examination, admission was the only other possible course to take.

When patients called the oncology ward during the day the decision to admit was often made after consultation with one of the medical staff on the ward or the consultant oncologist. Out of hours they were left to make the decision themselves

and they would often discuss the patient with other nurses on the ward and come to a collective decision. If they felt that the patient could be cared for in the community they would encourage the patient to call the DN or GP. If it was possible to avoid admission by offering an urgent clinic appointment or arranging for the Macmillan nurse to visit, these options were viewed as preferable.

Some nurses were concerned that primary care professionals may not have the knowledge or skills to deal with some problems. Antibiotic treatment for neutropenia was sometimes attempted in the community by professionals seemingly unaware of the seriousness of the condition, whilst others were concerned that spinal cord compression was not always diagnosed in time with serious consequences for the patient. However, the senior sister had a different perspective, suggesting that too many neutropenic patients were admitted who were not unwell and could be monitored at home. She felt a paradox was presented through providing a highly responsive service since it provided rapid access for the patients who needed it, but conversely it led to the deskilling of primary care teams.

5.5.3.3 Lung cancer nurse perspectives

The lung cancer nurse' perspective provided an interesting contrast. She cited many calls from patients who reported difficulties in securing a visit from a DN.

Sometimes when this occurred and she contacted the DN they seemed under the impression that no problems existed. Another prominent issue with her group of patients was anger over delayed diagnosis, this would at times lead to patients refusing to see their GP and preferring to rely on other services.

Part of her role was to run a support group for lung cancer patients and many of these patients she reported would contact her about problems which they faced in the community. Some patients requested that she visited them at home, which being based in the hospital she was unable to do, and some were reluctant to be referred to a Macmillan nurse for ongoing support. A proportion of her working time was spent helping patients to understand which service to call in which situation, since some patients had multiple contact details: DN, Macmillan nurse, GP, oncology ward, chemotherapy suite etc.

5.5.3.4 COPD nurse perspective

The interview with the COPD CNS provided a very valuable insight into the plight of patients with end stage respiratory disease. She had been appointed six months earlier into a role aimed at reducing emergency admissions, although she had 18 months experience in a similar post elsewhere. Patients were referred to her from the hospital or GP. The hospital referrals tended to be housebound patients having repeated admission, whereas those from GPs tended to be fitter and more active, able to visit the surgery. This caused her to reflect that GPs may be less aware of the needs of housebound patients.

Being the sole COPD CNS in the city she was only able to offer patients a few visits over 8 weeks, in which time she worked with them to develop coping strategies aimed at avoiding admission. Many of her patients were isolated, living alone and having no visitors. DNs were often not involved because the patient had no specific nursing needs.

DNs also recognised that non-cancer patients were relatively poorly served by their services and they were able to visit only if specific clinical tasks such as dressings, syringe drivers or treatment for constipation were needed. However, for terminally ill non-cancer patients whom they occasionally cared for, Macmillan nurses would still offer them valuable support.

Patients could contact the COPD CNS after discharge from her caseload; however, withdrawing the service after eight weeks caused great anxiety for many patients. However, she commented that she found the levels of fortitude and acceptance shown by her patients remarkable.

In her experience many patients dreaded admission, however when they were extremely breathless they became fearful and would view hospital as a place of safety. One of the aims given to her was to encourage patients to call their GP rather than an ambulance in these situations. However, she observed that waiting for the GP to call was the main reason why patients persisted in calling an ambulance, identifying this as a problem with no easy solution. Conversely she identified that some patients were not averse to hospital admissions. Some had developed social bonds with hospital staff and enjoyed the camaraderie of the ward, with hospital staff on one occasion visiting a patient at home in between admissions.

5.5.3.5 Social service provision

According to the COPD CNS many of her patients frequently received social service support, such as in preparing meals and help with personal care. Whilst patients were generally greatly appreciative of this care, on numerous occasions care was removed, e.g. reduction from three to two visits per day, without any clear explanation given to the patient.

DNs commented on their joint working with social services. The system had worked well when social workers in localities had worked with them and a relationship had been built up. Social services had however recently become more centralised, leading to less opportunity to work in this collegiate fashion. This made putting packages of care together across the health and social care divide more time consuming and problematic. One DN G grade sister reflected that dying patients needed sensitive and specialist care, which was not always available from social service carers. For this reason she felt much more confident if the community trust health care assistants from the Family Support Service cared for these patients rather than social service or agency staff. This services is the subject of the study in Chapter-6.

In none of the individual or group interviews were issues around failure of social services to provide home adaptations raised, neither did I ask interviewees directly.

5.5.4 Discussion

Key informant interviews gave very useful insights into the constraints of providing care to palliative patients in the community. The central role of the DN, GP and Macmillan nurse were highlighted by each group, apart from the COPD CNS who did not mention the role of the Macmillan nurse. Patient and carer interviews highlighted directly the complexity of the problems which they faced, whilst the complexity of the services available to provide care was apparent by implication; the key informant interviews highlighted the complexity of the services directly.

Organisational complexity emerging from overlapping and interacting services in the community was high. In addition this complexity was increased by marked variation in the practices of individual professionals, particularly GPs and the unavailability of some services at certain times of the week.

Whilst the practices and attitudes of GPs received the most prominent criticism particularly from DNs, they were not entirely happy with the Macmillan nursing

service either, especially its lack of 7 day availability, but also, because of the apparently more valued role of the specialist. In addition they illustrated that within the city tensions can arise between all the members of the 'supportive triangle' of DN, GP and Macmillan nurse. Understanding this more fully requires further research exploring the experiences and attitudes of Macmillan nurses and GPs. Oncology nurses and the lung cancer CNS raised concern about the knowledge, skills and effectiveness of DNs and GPs, although oncology ward nurses were more muted in their criticisms.

All the key informants corroborated the finding from the patient and carer interviews, that patients with advanced disease place high value on having a personal relationship with health care professionals which are constantly renewed through continuity of care. A variety of models exist which offer these relationships, including GP and community nurse, hospital ward and specialist nurse. Another feature which enhances these relationships is the ability to contact the professional or service when needed and without difficulty. There is also evidence from the oncology ward nurse interviews that patients, whilst valuing the expertise of the specialist, are apparently happy to be referred from the specialist oncology ward nurse back to a GP or DN. Perhaps this reassurance comes from knowing that the problem has been reviewed by the specialist before being referred back to the generalist or maybe it is simply a function of the accessibility of the specialist and the relationship the patient has with them. This is an area which merits further exploration.

The complexity of the issues highlighted in these interviews indicates that arranging services for palliative care patients is likely to be a challenging process. Programmes such as the GSF aim to enhance the organisation of community palliative care, by ensuring good channels of communication within primary care teams and between those teams and out of hours providers and specialists; by keeping a register of palliative care patients and by enhancing the skills of primary care practitioners in the delivery of palliative care (Thomas, 2003). Whilst the results from this study do support these objectives, they also highlight important relational issues which may frustrate the attempts to improve the delivery of palliative care through attention to organisational procedures alone. To gain a deeper understanding of these relational

issues, I will re-examine some of the emerging themes by drawing on Layder's theory of social domains as discussed in Section 4.3.6 (page 154), with particular reference to his framework for exploring relations of power.

5.5.4.1 Relations of power in delivering community palliative care

Layder considers power to be ubiquitous, coursing through and interlinking all four domains of society. Power has an enabling and a constraining effect on the actions and interactions of subjects arising both from within the subject as a result of their psychological 'make up' and personal history (*psychobiography*) and descending from structural elements of the *social settings* in which interactions (*situated activity*) take place, through the mediation of *contextual resources* made available to the actors within these settings. Thus:

'Each domain embodies a different form of power. Although individual and intersubjective forms of power belong to the domains of psychobiography and situated activity, we need to consider how they relate to the powers that derive from [social] settings and contextual resources. Since the latter are reproduced features of social life, they present power that has become historically entrenched in institutions and organisations. Such powers have endured over varying spans of history and represent established asymmetries structured around social relations, positions and practices. In varying degrees they are resistant to attempts to transform, modify or side-step their influence. Individual behaviour and situated activity exist within this envelope of more encompassing power relations. Thus episodes of social activity are a blend of individual, intersubjective and systemic (organisational or structural) forms of power' pp283-284 (Layder, 2006).

In Chapter-2 I explored the historical relationship between GPs and DNs, where traditionally the nurse was considered the 'handmaiden' of the doctor (Nolan, 1995). The subordination of nurses to doctors is thus a structural issue which has been apparent since the inception of nursing in the mid 19th century, although the seeds of this probably emerge from doctors being assisted by domestic servants before this time (Jones, 2003). Whilst the delivery of palliative care in the community has become located within the multidisciplinary team with DNs most directly engaged

with the patient, the dominance of the GP over the DN persists (Speed and Luker, 2006).

GPs largely retain control of prescribing and the clinical examination, e.g. DNs are not allowed to perform rectal examinations thus DNs (and Macmillan nurses) are reliant on GPs to perform these tasks. This can lead to dilemmas for DNs. For instance the scenario described in Box 5-11 (page 218) where a DN challenged a GP over what she considered unsafe prescribing, illustrates that DNs might have superior knowledge to GPs in areas of palliative care (Speed and Luker, 2006). However doctors may resent what is a challenge to their individual professional competence and that which will ultimately undermine the justification for professional dominance (Turner and Samson, 1997). Although it is the GP's responsibility to prescribe, nurses have responsibility to ensure they practice safely (NMC, 2002), thus presenting a dilemma for the DN concerned.

Ideally, the skills of the DN and GP are complimentary within the team with members showing mutual respect and working co-operatively for the benefit of patients (McWhinney, 1998). There was evidence from the DN group interviews that this characterised some teams, however, other teams were characterised by dysfunctional relationships, for example with GPs refusing to visit patients despite DN requests. Even when a good relationship existed, it was normally the DN who needed to wait for the GP to be free, rather than vice versa. We also found this was the dominant pattern in the GSF practice which we evaluated (Munday et al. 2007a).

DNs reported a variety of strategies for managing relations with GPs to gain the desired outcome to their needs. The method employed in this respect will no doubt vary according to the DNs psychobiography; thus the scenario in Box 5-11 (page 218) demonstrates one DN's assertive approach towards a GP, other DNs with less experience or confidence might not have felt able to challenge a GP so directly.

Some DNs would enlist the support of Macmillan nurses to make an assessment of the patient and to approach the GP to discuss further management. Interestingly this issue was raised with me in a discussion with a GP which I recorded in my field notes. He described how he felt his management of patients could be undermined by DNs bringing in the Macmillan nurse to see patients. For patients who the DN felt a medical assessment was mandatory and the GP refused to visit, the ultimate strategy

was to call for an ambulance, so that the patient could be examined in hospital. This however, could be seen as a failure for the DN, whose aim was to keep patients at home. Similar findings with regard to DNs approach to GPs have been recently reported by Speed and Luker (2006).

Whilst the issue of medical power over nurses is widely explored in sociological texts (Carpenter, 1993; Friedson, 1970; Turner and Samson, 1997), the issue is not one commonly examined amongst doctors themselves. The importance of doctors working effectively within a team, including showing respect for and valuing the contribution of other professionals was emphasised in the recent report on medical professionalism by the Royal College of Physicians (RCP London, 2005) and the GMC publication 'Good medical practice' (GMC, 2006). However neither of the publications comments on the structural relations of power between doctors and other professional groups within modern society and the effect that this could have on team functioning. McWhinney (1998) discussing 'core values in primary care' in the BMJ, expressed the need for members of primary care teams to adopt an 'aperspectival' approach in which all perspectives were considered equal; nonetheless he also fails to explore the issue of power relationships in this context. It is therefore probable that GPs rarely reflect on the effect of their power as doctors on their relationship with DNs.

The presence of differential power between DNs and Macmillan nurses was also evident. This was manifest by DNs enlisting the support of Macmillan nurses to approach the GP to achieve what the DN felt she could not. The GP in the example in Box 5-11 (page 218) challenged the legitimacy of the DNs views on medication, since she was not a Macmillan nurse and therefore did not have the status to challenge his practice (whether he would have accepted a challenge from a Macmillan nurse is a moot point). This differential between DNs and Macmillan nurses arguably represents the inherent valuing of the work of the specialist over the generalist (Willis, 1995) and the more technical (biomedical) role of the Macmillan nurse over the caring role of the DN (Davies, 1998). The higher value of the specialist Macmillan nurse over the generalist DN is also reflected in the community trust employment policy at that time; the highest grade for DNs was G, whilst all

Macmillan nurses were H grade, even though the duties of DN team leaders arguably merited at least the same grading.⁴

The general tenor of teamworking between DNs and Macmillan nurses in comparison to that between DNs and GPs emerging from the key informant interviews was one of co-operation rather than confrontation. However, there is evidence that this collegiality is threatened if DNs feel they are being treated as the Macmillan's 'handmaiden'. Whilst much discontent with the relationship between GPs and DNs was expressed, no DN challenged this relationship in such an emotive fashion. This arguably reflects a deeply engrained cultural acceptance of the status of doctors by DNs, whereas the perceived differential between specialist and generalist nurses leads to resentment. Also it is possible that as I am a doctor, DNs were more guarded in their criticism of GPs.

The power relationships which exist between patients and professionals are also apparent in this study. Patients comment on the relative inaccessibility of GPs and the reluctance to do home visits. The power associated with the gate-keeping role of the GP's receptionist which is common coin within British culture (Arber and Sawyer, 1985) was evident from patient narratives (Box 5-4 Patient 32 page 200). Similarly the triage experience of patients out of hours can be seen as a barrier to accessing GPs (Worth et al. 2006). Receptionists need to question patients or their carers and make a judgement about the urgency of need following guidelines set down by the GP practice or out of hours provider. This is an area of tension between patients and receptionists (Arber and Sawyer, 1985) and is likely to be manifest in displays of power as receptionists seek to fulfil their duties of gate keeping and patients seek access to a doctor. Receptionists have indicated that the most challenging part of their work is dealing with 'difficult patients,' whilst they frequently rely on their own resources to perform their duties, since few receptionist report that they have had training in communication skills (Eisner and Britten, 1999).

Conversely patients who have regular contact and ready access to DNs seem happy that this is the way their care is managed with most feeling reassured that the DN can get hold of the GP if necessary. One patient commented on how DNs and Macmillan nurses are privileged in their access to GPs (Box 5-4, Patient 55 page 200) compared

⁴ This was expressed to me by a senior nurse manager within the trust.

to her own experience. However, it seems that the tensions in the relationships within the supportive triangle are largely invisible to patients or possibly they did not feel able to comment directly within the hospital especially as they knew I was a doctor also.

Patients with non-cancer diagnoses were less likely to have regular contact with professionals than cancer patients. This seems to be a structural issue. Cancer patients often received DN input because they had needs which fulfilled a task based approach and once the DN was visiting she was also able to monitor the patient's general condition and maintain the relationship. In addition open access to oncology wards designed to deal with treatment complications is an advantage for cancer patients who have another service to call if necessary. Since having ready access to a trusted health care professional (HCP) who can act as an advocate, source of information and advice, and someone to call when necessary were central to accessing appropriate services, this relative empowerment for cancer patients leaves non cancer patients relatively disempowered.

Whilst general structural issues influence the power of the majority of patients, some by virtue of their personal status or knowledge of 'the system' were relatively more empowered. Some patients had enhanced access to services due to relatives being HCPs, one cancer patient who was a HCP, when unsatisfied with the GPs assessment called the consultant oncologist, conversely another patient felt 'a nuisance' for having to contact the GP. Patients preferring hospital admission to remaining in the community could use the 'trump card' of calling an ambulance. Thus various ways exist for the patient to access services, based on their personal relationships and knowledge of the system. These 'empowered acts' arising from the patient's psychobiography may modify the effects of general structural issues, although not necessarily without frustration and stress for the patient.

Exploring the ontological depth of the issues involved in delivering and receiving palliative care in the community thus adds insight to the more instrumental considerations of service provision. Many of the issues which frustrate good community palliative care result from social structures through which power relationships between HCPs and between patients and the health service are mediated. Social structures are continually reproduced through ongoing social

activity; however it is within the power of individual practitioners, particularly GPs to facilitate the production of altered structures at the practice level, which are more conducive to effective palliative care. This might be achieved by attention to several issues. Firstly, regular contact between the GP and the patient to review their condition and instil confidence that the GP is aware of their current state of health and involved in their care; secondly, giving palliative patients and their carers rapid and preferential access to the GP, through robust practice based procedures by which patients are identified and known to practice staff; and thirdly, a close working relationship within the supportive triangle with a policy of providing patient visits as required. These actions can be mutually reinforcing and result in structural alterations facilitating rather than obstructing the delivery of effective care and providing the context for a proactive approach, through advance care planning. Whilst GPs have identified programmes such as the GSF as enabling them to address these issues (Walton, 2005) others are concerned that the new GP contract may mitigate against it (Heath, 2004; Freeman et al 2003).

I have also argued for a reflective and open approach where practitioners are aware of how power can both facilitate and constrain good care. Whilst enhanced training in multidisciplinary team work has been recommended as part of the undergraduate medical curriculum (RCP London, 2005), this should include an exploration of theories of power to enable students to be aware of the effect of social structures on the functioning of society and the dominant position of the doctor in relation to other professionals. This combined with training in a reflexive approach to allow continuing examining of relationships with other HCPs would complement the approach to integrated learning which is currently encouraged. Through this process the next generation of doctors may become more collegiate in working with other HCPs and more aware of issues of power.

5.6 Conclusion

The multi-methods research in this chapter has provided insights into a previously sparsely researched area and has demonstrated the complexity involved around the admission of palliative care patients. The survey provided an overview of the demographics of those admitted, whilst the interviews with patients and carers enabled exploration of the experience leading up to admission and to illuminate

contextual issues which affect the patients' experience of living with advanced disease in the community. The findings challenge the assertion that patients are admitted to hospital to die as being an over-simplified truism. Key informant interviews provided insights into the experiences of HCP in delivering services to these patients and enabled triangulation to test and develop the themes emerging from the patient interviews. Finally, an exploration of issues of power, using Layder's domain theory has enabled a depth realist exploration of the issues facing patients, carers and HCPs which moves beyond the instrumental.

The insights from this study have facilitated service development in several ways. A seven day a week palliative care service was established in 2005, with Macmillan nurses, supported by consultants in palliative medicine working at the out of hours centre where they can develop good working relationships with on-call GPs. In a recent audit this services was highly evaluated by GPs and DNs. Insights from the study have strengthened the approach of the palliative care team in working with primary care teams and are influencing work being undertaken with community heart failure specialist teams to provide palliative care to their patients. Whilst we also plan to work more closely with the COPD CNS service, major changes within the PCT have meant this work has not yet been feasible.

Further research into the experiences of unscheduled care in the community by patients, carers and health care professionals conducted within the palliative care team has enabled a further study to be initiated to explore the complexities involved in delivering community palliative care. A draft report for this project is made available in Appendix-2 (page 314). The important role of health care assistants providing home care for patients and their carers as identified by DNs in their interviews has also been explored by the community palliative care team. This project forms the subject of the next chapter.

Finally experiences working with a variety of health care professionals in the study, the majority of whom were highly supportive, interested in the project and insightful into the complexities inherent in community palliative care enabled me to develop the vision of developing a community of research practice as exemplified in the next chapter and discussed fully in Section 7.6 page 301.

Chapter 6 - Health care assistants in community palliative care: invisible workers, emotional labourers

6.1 Introduction

In 2002 I was appointed as consultant in palliative medicine for the city PCT. This presented me with further opportunities to explore research and service development in community palliative care, but now in the context of a palliative care team in which I was a member. This was the first project which has been undertaken by the emerging community of research practice (Section 7.6 page 301).

Within six months of taking up my new position, a senior manager within the city requested that we looked at developing a service to provide home based respite care for palliative care patients. The PCT already had a service called 'Family Support' (FSS) which was part of the intermediate care service (ICS) and which had been highlighted in key informant group interviews with DNs (Section 5.5.3.5 page 222). FSS employed health care assistants (HCAs) to undertake 'sitting' duties in the city and was accessible to DN staff on behalf of their patients. This service, which provided care for adult patients with any diagnosis, was well established and was apparently highly valued. We decided to explore the effectiveness of FSS and the possibilities for developing it. The alternative was to develop a hospice at home service with the local hospice although after initial exploration it was clear that this would be the more expensive and complicated option.

Initially we conducted a retrospective review of all of the referrals to FSS in 2002, following which we performed key informant interviews to explore DN and discharge planners' views of the service. As a result of this initial work we obtained funding to develop a home care facilitator (HCF) post to provide support and education services for HCAs working in FSS with palliative patients. We decided to develop the HCF role using an action research approach to achieve a robust service, empowering HCAs by enabling them to be involved in the development and evaluation of their own support system and also to gain deeper insights into the work and support needs of HCAs working in patients' homes, an area which had received little attention in the literature.

In this chapter I will present the results of semi-structured interviews with HCAs working in FSS undertaken by the HCF and a research fellow (RF) which explored the issues HCAs face in caring for palliative patients. I will examine these issues using Layder's domain theory and the theory of emotional labour.

Initially I will present a review of the general literature regarding HCAs and then more specifically the work of HCAs in palliative care. This will lead to a review of the concept of emotional labour in healthcare and palliative care. I will then briefly describe the background of the FSS and some of the issues which have arisen for HCAs working within it. Finally, before describing the methods and results of the interview study with HCAs, I will summarise the studies undertaken before the HCF was appointed as these studies reveal important contextual details for the HCA interviews. In this Section (6.4.1 page 248) I will also discuss some of the issues which have emerged in using a practitioner research approach in this context.

6.2 Health care assistants (HCA) a literature review

This review will consider the HCA role, national policy regarding employment of HCAs in the NHS, issues regarding training and the relationship of HCAs with trained nursing staff. Finally, a brief review of HCAs within community palliative care in the UK is presented. This literature was sourced using Medline and Cinahl employing search terms 'nurse aids' and 'palliative care' and 'health care assistant' as a key words and by accessing Department of Health and NHS websites. Reference lists of the articles obtained were inspected for relevant papers and documents. These articles were also retrieved and scanned.

6.2.1 The HCA role

There has always been a blurred boundary between nursing and ancillary duties and untrained staff have always been relied upon to undertake some nursing roles. In 1955 the role of nursing auxiliary (NA) was established with a national pay scale and review body as for trained nurses and by the 1980s NAs formed around 25% of the total nursing workforce in the NHS (Thornley, 2000).

Health care assistants were introduced through the NHS and Community Care Act (1990) necessitated by Project 2000 through which nursing became a graduate profession and student nurses no longer provided a large workforce within the NHS

(Arblaster et al. 2004). At the same time a parallel grade the support worker (SW) was introduced; both HCA and SW (the terms are used interchangeably) being originally intended to perform ancillary rather than nursing tasks. Thornley (2001) proposes that the term 'nurse' or 'nursing' was omitted to distinguish these grades from qualified nurses during the rise of the 'new professionalism' in the discipline. As with the NA grade, pay is set nationally (Thornley, 2001), although it is apparent that HCAs on average are paid slightly less than NAs (Thornley, 2005).

A range of other titles are used: 'generic support worker; clinical support worker; healthcare support worker; care team assistant; nursing assistant; ward assistant; theatre assistant; community care worker; home carer; scientific helper; doctors' assistant; and even "bedmaker"' p453 (Thornley, 2000); furthermore there is no clear distinction between NA and HCA roles. Thus identifying which staff within an organisation are HCAs is problematic leading to difficulties in conducting surveys of their role (McKenna et al. 2004). No accurate official statistics exist indicating how many HCAs there are working in the NHS (Crossan and Ferguson, 2005).

Although HCAs were originally intended to fill an ancillary role all the evidence points to them undertaking a range of nursing tasks. In 1992, a study by Dewar (cited in Crossan and Ferguson, 2005) on a psycho-geriatric ward suggested that trained and untrained staff fulfilled similar roles with the exception of the administration of medication which was undertaken by trained staff. Data collected from a national questionnaire study and in depth interviews with HCA and managers across 42 trusts reported by Thornley (2000) reveal the varied extent of HCAs' duties (Box 6-1). The wide range of duties undertaken by HCAs is also reported in other studies undertaken in the community (McIntosh et al. 2000) and in hospital (Spilsbury and Meyer, 2005).

'Giving drugs without supervision running clinics single-handed; phlebotomy; running therapeutic groups; organizing and chairing client review meetings; training agency staff on nights; giving advice on the phone; setting up all instruments for theatre; making up instrument trolleys for doctors; computer evaluations; acting as scrub nurse; tracheotomy emergency suction; writing care plans and keeping them up to date; initiating admissions and discharges; speech therapy assessment; venepuncture; plastering; ECGs; massage in cardiac arrest cases; preparing patients for suturing; being in charge of a shift; assisting mothers with breast feeding; dealing with doctors; infection control; going on ward rounds with doctors and being asked for views; restraining aggressive patients; setting up diagnostic machines and feeds; looking after student nurses and newly qualified nurses' p454 (Thornley, 2000).

Box 6-1 - The range of duties undertaken by HCAs

Several studies have highlighted HCAs as being predominantly mature staff, the majority being 30 or older, four fifths being women with a wide experience both in formal and informal caring roles (Thornley, 2005; Fowler, 2003; Spilsbury and Meyer, 2005). There is evidence of a high mobility in HCA posts with a yearly turn over of 21% found in a study across four London hospital trusts (Fowler, 2003). However a substantial proportion of untrained staff express the wish to do RN training given the appropriate circumstances (Thornley, 2005; Fowler, 2003); although many feel unable to avail themselves of that opportunity because of family or financial considerations (Thornley, 2005). Indeed in Fowler's study, 30% of HCAs possessed the qualifications necessary for RN training and 10% were graduates in areas other than nursing.

6.2.2 HCAs and health policy

Fundamental changes in health service provision in the last 20 years have encouraged the expansion of the role of untrained nurses. McKenna et al. (2004) suggest that this is for complex reasons including staff shortages and drives for cost effectiveness. A shortfall in the nursing and midwifery workforce existed in the 1990s as a consequence of a lower number of recruits, poorer retention, advances in medical technology, an ageing population, retirement of registered nurses, and the extension of roles to assume new responsibilities previously undertaken by doctors.

Employing HCAs was also considered to be an effective way of enabling trained nurses to spend longer periods of time with patients, through freeing them from ancillary tasks (McKenna et al. 2004). The Wanless report into the future of health in the UK also stressed the need to increase the flexibility of the workforce and for HCAs to substitute nurses for around 10% of their workload by increasing the number of HCAs employed by 12.5% (Wanless, 2002).

However, problems have been highlighted with the pursuit of this course. Firstly, the vision of HCAs allowing nurses to spend more time with patients has not been achieved in practice, since nurses performing increasingly administrative and co-ordinating roles has led to patient contact being undertaken by HCAs themselves (Spilsbury and Meyer, 2005). Secondly, NHS trust policies defining the specific roles for untrained staff have not always kept abreast of clinical or workforce needs. For instance, McIntosh et al. (2000) found that even though delegation of tasks for NAs within community teams evolved through trust policies which allowed a degree of flexibility, it was driven by a combination of workforce planning and workload management, such that it...

‘..occurred in an uneven and ad hoc manner and resulted in inconsistent use of the skills across district nursing teams’ p788 (ibid).

Thirdly, HCAs working in both hospital and community teams have been identified as potentially lacking support and supervision by senior trained nurses (McIntosh et al. 2000; Spilsbury and Meyer, 2005), a factor which may be overlooked because of HCA experience and apparent competence in performing clinical procedures, and their usefulness and flexibility especially at times when workload is heavy. Finally, in addition to a lack of formal qualifications or training for HCAs, there is no system for HCA registration or regulation. This remains the case, although a consultation exercise on HCA regulation was held by the Department of Health in 2004. Despite original plans¹ no policy was announced as a result, although work in Scotland is currently being undertaken to resolve this issue (Scottish Executive, 2006).

The effect is that although HCAs form a substantial and important part of the workforce on whom the NHS depends, they remain ‘invisible workers’ (Thornley, 1997), largely unrecognised for the work they perform. Thus, HCAs despite lack of

¹ Nursing and Midwifery Council News July 2004 Page 8.

clarity as to their roles are performing complex nursing tasks, unregulated, often unsupervised and formally untrained.

6.2.3 HCAs and training

No national minimum educational requirements exist for HCAs. The explanatory document for potential applicants states that all that is required is a good general education and suggests that initial training is likely to be on the job with a possibility of day release courses and/or private study (NHS Careers, 2004). Evidence suggests that the training available is largely trust specific (McKenna et al. 2004), with some trusts enabling HCAs to undertake National Vocational Qualification (NVQ) also introduced in 1990 (Thornley, 2001).

Training for HCAs varies both across and within trusts (Fowler, 2003). Little literature describing such courses is available, as might not be unexpected given the invisible nature of HCA work, making it impossible to explore this issue in detail. NVQ certificate training is available in five levels (1-5), with level two commonly considered relevant to the basic HCA role, identifying the 'holder as competent to undertake a range of duties in a care environment' p455 (McKenna et al. 2004). There seems to be a marked variation between NHS trusts in the availability of such training for HCAs (Thornley, 2000; Fowler, 2003) although a slow increase in the availability of NVQ training has recently been reported (Thornley, 2005).

Possession of a higher level NVQ does not always equate to higher grading or recognition, although it may lead to an informal split between 'trained' and 'untrained' HCAs and increased blurring between trained and untrained staff (Warr, 2002). A lack of reward for training can reduce preparedness to undertake NVQ certification (Hancock et al. 2005) and has been identified as a serious issue leading to low morale and plans to leave NHS employment (Thornley, 2005).

6.2.4 Relationships between HCAs and RNs

The increased use of HCAs within the health care setting has impacted on the work of trained nurses. Nurses have acknowledged that they rely on the work of HCAs on the one hand, but work to maintain the distinction between them and HCAs on the other (Spilsbury and Meyer, 2005). Daykin and Clarke have suggested that whilst there has been a change within nursing to allow nurses to practice with a degree of

autonomy taking on some of the traditional roles of the doctor, HCAs performing roles normally undertaken by trained nurses has potentially led to an undermining of the professional status of nurses. Thus the 'nursing literature has reflected an ambivalence about the involvement of health care assistants in the delivery of care' p350 (Daykin and Clarke, 2000). Similarly nurses although supportive of HCA education, might be reluctant to be personally involved (Coffey, 2004) or more predisposed toward student nurse training in comparison to that of HCAs (Spilsbury and Meyer, 2005).

Power differentials are evident in the relationship between nurses and HCAs, with nurses failing to recognise or give credit to HCAs for their skills; for example when the ward is understaffed the HCA is expected to undertake an extended role, whilst when it is fully staffed their competencies are ignored (Spilsbury and Meyer, 2005). HCAs have been reported as using strategies such as withholding information or sharing it selectively with trained staff as a form of control (ibid).

Whilst relationships between nurses and HCAs in the work situation can be ambivalent, those between HCAs and nursing institutions have been slowly evolving in recent years. Until 2000 HCAs had not been able to join the Royal College of Nursing (RCN) although that year a ballot of members overwhelmingly voted in favour of allowing HCAs at NVQ level three into membership. HCAs are now able to join the RCN if they have a level one qualification or they are working towards level one.²

6.2.5 HCAs and palliative care

In the field of palliative care as in all other areas of health care, untrained staff fulfil an important role. HCAs and NAs work within varying settings including hospices (James, 1992), community (Clark et al. 2000) and care homes (Miskella and Avis, 1998; Davies and Seymour, 2002), with each setting involving different types of work. As in other health care settings few studies describe in detail the work of HCAs in palliative care. Miskella and Avis (1998) interviewed eight HCAs in four nursing homes about their experiences of caring for dying residents. They discovered similar issues to those emerging from studies of HCAs in general settings. All had

² RCN Website: <http://www.rcn.org.uk/whyjoin/yourmembership/category30.php> (Accessed 14/05/2007)

initially learned their role through experience, although a few were undertaking NVQ training and all felt that they had been inadequately prepared and were keen to undertake further training. They also reported low levels of supervision by trained staff.

Untrained nursing and social care staff provide care in the community for those needing help with activities of daily living, monitoring to ensure safety and encouragement to achieve optimum physical functioning. Such care is commonly needed for the elderly and people with chronic physical and mental disabilities (McCluskey, 2000) including those at the end of life. For this type of care there is often a large degree of overlap between social and health care, with similar roles being filled by carers employed by social service and health care organisations and a blurring of the boundaries between the two (Clark et al. 2000).

Training within palliative care for HCAs in all settings tends to occur on a locality basis with little known about the different types and styles of course. There is evidence that HCAs are keen to receive training in palliative care and that palliative care courses are well received (Dowding and Homer, 2000; McCready and Macdonald, 2002; Miskella and Avis, 1998). Training programmes for palliative care in care homes involving HCAs have been recently developed (Hockley and Froggatt, 2006; Froggatt, 2000) some utilizing an action research approach (Hockley and Froggatt, 2006). This area has become a focus for the End of Life Care Programme (EoLCP) (Froggatt and Payne, 2006).

Patients at the end of life who require care at home, are frequently provided with 'sitting services' where the healthcare worker stays with the patient for prolonged periods, helping to care for their personal needs, providing company and allowing their carers to take a break from caring. This falls under the general rubric of 'respite services'. These services are highly variable and often employ a mixture of trained nursing and untrained health or social care staff (Ingleton et al. 2003), some are linked with specialist palliative care teams (Hockley, 1997) and others provided by charities such as Marie Curie Cancer Care (MCCC) (Higginson and Wilkinson, 2002). Such complexity leads to difficulties in evaluation, with comparisons being problematic as many studies fail to give an adequate description of the type of service or the local context (Ingleton et al. 2003).

9.22 Services should have the capacity to provide intensive coordinated home support to patients with complex needs who wish to stay at home. Such support may be needed to respond to a crisis in the care of a patient at home, for the last few days of terminal care, or for longer periods. A range of co-ordinated inputs will be required, but will generally involve:

- the specialist palliative care team
- *practical nursing care and support for extensive periods throughout the day and night*
- the patient's GP
- support from other services, such as those provided by social services departments.

9.23 To achieve the capacity set out in paragraph 9.22, commissioners may need to increase the level of home services available. *For patients with advanced cancer, practical nursing care and support for extended periods may be provided by staff from a local hospice, the Marie Curie Nursing Service and others. In many cases, home nursing and hospice at home services may work closely together and some providers may offer both.*

NICE (2004) p126 (*Note: italics are added to illustrate relevant text – rest is given as context*)

Box 6-2 - Home care services in NICE guidance 2004

Sitting services provided by this group of workers are identified as a vital element of care which enables palliative care patients to remain at home. This type of service is recommended by NICE in its guidance on supportive and palliative care in cancer³ (NICE, 2004) (Box 6-2).

Harding and Higginson (2003) in a systematic review of carer support services only identified two examples of sitting respite services using untrained staff which had

³ It is interesting to note that this is the only recommendation for home care sitting services in the NICE guidance. It is not explicit regarding the type of duties staff might need to perform, the type of staff who should be employed for this role, nor does it address issues such as training and support for such staff. This is perhaps significant as the lack of literature regarding the role of these staff and the lack of standardisation of the role are very noticeable features arising from this study.

been evaluated. One study of a service using volunteers (Johnson, 1988 cited *ibid*) demonstrated high levels of satisfaction amongst carers but also high levels of burn out amongst volunteers. The other study by Clark's team (Clark et al. 2000; Ferguson et al. 1998) evaluated seven Macmillan carer schemes in which HCAs provided care for cancer patients and others with advanced disease, with the aim of supporting patients and their carers, enabling home care during 'critical stages of their disease' p130 (Clark et al. 2000) and allowing patients to die at home. The service was provided especially to 'plug gaps' which were left by existing services. Various arrangements were made for access to the service, with some services being more closely aligned with specialist palliative care than others. They identified three areas in which HCAs worked:

"intimate care (bathing, washing, toileting, feeding); *social and emotional support* (listening, talking and providing companionship) and *practical help* (preparing meals and light refreshments, tidying the house and shopping)" p138 (*ibid*).

Family carers evaluated the service highly, indicating that they felt able to leave the patient with the HCA and they would not have coped well with care in its absence. Twenty percent of carers were of the opinion hospital admission had been avoided. Two 'potential' problems were identified in a semi-structured interview study with HCAs delivering the service; firstly, the possibility of having to deal with complex clinical tasks beyond their experience and training and secondly, the difficulties arising from straddling the health and social care boundary (Ferguson et al. 1998). Such 'bureaucratic structures' were seen by the authors as a threat to a flexible service which enabled continuity to be established, by allowing a multiplicity of tasks to be performed by one carer. Whilst their hope was that a new climate of intersectoral partnership may enable such schemes to flourish, the climate may not be substantially different nearly ten years later.

6.2.6 Postscript

HCAs and NAs perform many important functions within the UK health care workforce including palliative care, but with little formal recognition of their skills or their support and educational needs. It remains to be seen whether a satisfactory

solution for HCA status, regulation and training can be achieved which will reward HCAs justly for their work and enhance the working relationships between HCAs, trained nurses and others, but which is affordable within the resource constraints which were part of the rationale for expanding the HCA grade. It remains to be seen whether HCAs once professionalized through training and regulation will be happy to remain paid at between 50 and 60% of the salary of a trained nurse. HCAs at present remain 'invisible workers' performing an essential task whilst the surveillance culture of the early 21st century conveniently fails to notice. As McKenna et al. (2004) conclude:

"The HCAs themselves are powerless, waiting on policy-makers to sort out the mess while they do their best to be part of the nursing family. In the meantime, the lack of a recognized training programme, regulation and their undefined role put patient quality and safety at risk" p 457.

6.3 Emotional Labour

As Clark et al. (2000) highlighted, HCAs providing sitting services for palliative care patients in the community offer emotional support. I will explore emotional support in HCA work using the theory of emotional labour in Section 6.8.3 (page 268). In this section I will explore concept of emotional labour and the broader issues of emotion and power.

6.3.1 Emotion and power

'Power is ever present [in social life] and emotion is its natural partner' p17 (Layder, 1997).

Power as Layder asserts is ubiquitous and is implicated in all social relationships. I explored issues of power between health care professionals and patients in Section 5.5.4.1 (page 224). In this section I will explore emotion and its place in social relationships. Whilst power is most evident as a product of structural factors within social life, emotion is embedded in and arises out of the domain of psychobiography; it is contingent on experience, memory and psychological make up generally.

Emotion and power are natural partners suggests Layder, a feature which can be seen in various ways. In all relationships Kemper (cited in Lupton, 1998) suggests, emotions will flow according to the relative transfer of power. If one actor senses

that they are losing power this is accompanied by a feeling of anxiety or fear, whereas the actor who gains it is likely to have a sense of security. Power may also be evident in the *use* of emotion in social interaction at the personal level, for instance losing one's temper in an argument may either increase or decrease one's future power within a relationship. Emotion may be consciously used as a form of power to manipulate others as may be seen in the popular press rousing fear about social change by the 'swamping' of society by asylum seekers and it may be used by charismatic leaders to manipulate their followers (Layder, 1997) or by charities attempting to raise funds for areas of natural disaster or hospice care.

Emotional displays are modified by appropriate 'feeling rules' p56 (Hochschild, 2003), which will vary according to the situation faced, e.g. joy at a birth, sadness at death etc. Whilst these are basic human emotional instincts their expression is culturally specific. Their immediate expression is shaped by the social setting in which the event takes place (or in which it is reported) and are constrained or enabled by contextual resources. For instance, chastisement of a child may result in tears in the privacy of the home, but a nonchalant grin if his peers are present, where the rule of 'not blubbing' may firmly constrain his emotional display. Displays of emotion normally involve intersubjective interaction and are communicated in appropriate ways: smiling, shouting, crying, laughing, hugging etc; all modalities by which emotion - arising from joy, fear, love, anxiety, pride, shame etc - is communicated. Lupton (1998) suggests that theories of emotion are most usefully divided into two types: biological theories and theories of social construction. Biological theories view emotion as an inherent human instinct with universal expression, often arising out of animal behaviour: aggression, submission etc. Conversely, theories of social construction see emotion as a social phenomenon emerging from cultural norms and practice. Rejecting either type of theory as incomplete in itself, Lupton adopts a blended approach to emotion. She takes a broadly poststructuralist perspective in which she incorporates a concept of the interaction of 'sensual embodiment' and 'the influence of the unconscious in emotional experience' p38 (ibid). Hochschild (2003) similarly adopts a view of emotion as biologically innate drawing on Darwin and combining this with an interactionist approach, where emotion is produced through interpersonal activity.

Layder's combination of both power and emotion provides an extremely rich view in which all of his social domains are implicated. Not only is emotion affected by power, but it is firmly linked to psychobiography in which personality and experience influence its 'sensual embodiment'. It is also modified by the social settings in which the emotional interaction takes place and the cultural resources available to the actors. Utilizing domain theory will enable me to take a realist approach to exploring the emotion work of HCAs.

6.3.2 Emotional management

Whilst all humans are emotional beings, not all people manage their emotions in the same fashion. Individuals do vary in their *ability* to read and handle emotions in themselves and others. McQueen, writing about emotional management in nurses, suggests that there are two aspects to this: interpersonal and intrapersonal (McQueen, 2004). Interpersonal management involves the ability to understand the emotional state of another and to work well in co-operation with them or conversely to manipulate them successfully. Intrapersonal management is the ability to be self aware, to recognize one's own feelings, perceiving how they affect social interaction. Interpersonal and intrapersonal emotional management will be interlinked and mutually reinforcing – either negatively or positively. Such emotional management is a central feature of emotional labour and the extent to which it is successfully or unsuccessfully completed. Health care workers skilled at such emotional management will also 'become aware of their own values and prejudices' p102 (McQueen, 2004).

McQueen's proposition whilst helpful draws on the construct of emotional intelligence (EI) which is problematic. EI was originally proposed by cognitive psychologists Mayer and Salovey who were interested in the link between emotions and cognition: *emotion*, i.e. feelings, with *intelligence*, i.e. the ability to reason based on knowledge (Mayer et al. 2000a). EI was popularized in the last decade by science journalist Daniel Goleman (Goleman, 1996; Goleman, 1998). His work was highlighted and brought to prominence by an article in Time Magazine, entitled 'The EQ factor: new brain research suggests that emotions, not IQ, may be the true

measure of human intelligence' and highlighted on the front cover⁴. This brought emotional intelligence to the notice of the business community and has spawned a plethora of emotional intelligence books and internet resources.⁵

Whilst EI is in common use some of the issues associated with the term are problematic and there tends to be a conflation of all aspects of emotional management into this one construct (Mayer et al. 2000b). In addition, claims that EI accounts for 80-90% of success (Goleman, 1998) have not been substantiated, with Mayer et al (2000b) suggesting that for business success the independent predictive value of EI is only 2-3%.

Emotional intelligence is a concept now used widely in the workplace seemingly applied without critical examination (Hughes, 2005). Tools to measure emotional quotient (EQ), many of which have not been adequately validated (Mayer et al. 2000b), are used for screening and selecting employees for recruitment or promotion and EQ has been explored (unsuccessfully) as a method of screening prospective medical students (Newsome et al. 2000). This process of reducing the complexity of emotions to a numerical score has been identified as part of a trend of reductionism within society in general and commercial life in particular which since largely unchallenged has been interpreted as a 'Foucauldian snare' (Fineman, 2004).

It is not within the scope of this thesis to examine the issues surrounding emotional intelligence in greater depth, however it has been important to highlight some of the main issues, because it is a concept that has been uncritically used in both the nursing and medical literature (McQueen, 2004; McMullen, 2003; Strickland, 2000; Epstein and Hundert, 2002). Strickland (2000) writing about health care management seemingly falls into the trap of stating that 'emotional intelligence is twice as important as a person's intelligence quotient and technical skills combined' p112.

Whilst emotional management is important in health care work and particularly so in the work of HCAs in palliative care, the term emotional intelligence should probably be limited to the original definition of Mayer and Salovey to avoid a concept so broad that it has been taken to mean any ability to deal with emotion, personality or mood.

⁴ Time Magazine October 2nd 1995.

⁵ A search on amazon.co.uk (26.05.06) revealed 265 titles on Emotional Intelligence – Goleman's were the top three.

6.3.3 Emotional labour and health care

Emotional labour is work undertaken in which the emotions, e.g. warmth and empathy or (conversely) aggression, are central and need to be managed in a specific fashion, either by containing or by projecting them, whether or not they are felt. Any worker involved in face to face encounters with clients will engage in emotional labour in order to perform their role effectively.

Emotional labour was originally conceptualized in 1983 by Hochschild and defined as 'the management of feelings to create a publicly observable facial and bodily display' p7 (Hochschild, 2003). She suggested that occupations in which emotional labour takes place have the following features:

'First, they require face-to-face or voice-to-voice contact with the public. Second, they require the worker to produce an emotional state in another person — gratitude or fear for example. Third, they allow the employer, through training and supervision, to exercise a degree of control over the emotional activities of employees' p147 (ibid).

Hochschild's first example is that of the female air steward, who is expected to display a warm affect to all customers, engendering a sense of well being, personal importance and trust. Airlines regard the steward as the public face of their company, expecting her to undertake emotional labour to maintain this feeling in customers even when they are demanding or unpleasant or conversely the steward is feeling anxious, sad or angry. Emotional labour is not only related to feelings of wellbeing; Hochschild's second example was one of the debt collector whose demeanour is intended to produce a feeling of apprehension in the client, so that they will settle their debt.

Emotional labour in nursing was explored in depth by Smith (1992) researching the work of student nurses through participant observation. She noted how emotional labour was not considered 'real work', emotional skills were rarely included in student training and emotional support for the student was rarely offered. This resulted in dissonance between student's aspirations in entering training and their experiences, leading some to lose their initial idealism and others to leave before training had been completed.

In relation to palliative care and dying emotional labour is also an important concept and this has been explored by a number of authors (e.g. Smith, 1992; James, 1992; Froggatt, 1998; Kelly et al. 2000). Smith describes work in supporting patients around the time of death as ‘the ultimate emotional labour’ p92 (Smith, 1992).

James (1992) in her seminal article on caring in hospices describes how emotional and physical labour are dual aspects of caring in this setting. Physical labour, i.e. performing tasks becomes both ‘work’ and ‘framework’ where the task (e.g. bathing a patient) forms the opportunity for emotional labour. Even in the hospice, nursing work which does not involve a specific practical task might not be considered as real work, e.g. talking to a patient. James also points out that skill in emotional labour is not necessarily the province of the most senior staff members:

‘At the hospice at the time of the study there was almost an inverse law of status and skill in emotional labour. The temporary medical director explained that he was "no good at that kind of thing" [i.e. disclosure], and the relatively better-paid, higher status, but young staff nurses relied on the four older auxiliaries who were described as the “backbone” of the unit’ p503 (ibid).

Thus managing emotions was reliant on those with least status (and power).

6.3.4 Emotional labour and HCAs in community palliative care

Emotional labour is central to the role of HCAs providing sitting services in the community. Ferguson et al. (1998) interviewing Macmillan carers, the only study which partially mirrors⁶ the study presented in this chapter, indicate how ‘emotional support’ was reported by the participants as being an important aspect of their work, which included ‘talking, chatting and offering companionship’ and the concept of ‘just being there’ p12 (ibid). They also mention how patients and carers occasionally asked searching questions about prognosis which could put the HCA in a difficult position and acknowledge that their role could be emotionally draining. However, they do not develop the concept of emotional labour, nor explore in depth aspects of the emotional work which HCAs undertake. I will therefore explore emotional labour and the HCA through the data presented in this study in Section 6.8.3 (page 268).

⁶ Whilst Macmillan carers were identified as being HCAs they also performed more socially directed roles, such as cooking, going on errands, child care and accompanying patients on visits. Whilst HCA in this study occasionally performed some of these duties, they were not officially within the scope of their role.

6.4 Background to the Family Support Service

The Family Support Service (FSS) of the PCT was established in 1992 with the remit of providing home care sitting services for all appropriate patients in the community. The service was designed to supplement Marie Curie home nursing services which were only available for cancer patients at the time.

Initially FSS was a 'stand alone' service, employing a few HCAs on a bank system, where work would be provided as it became available. FSS led by a qualified nurse with secretarial support was operated from the office of the senior nursing manager who established the service. These arrangements although informal were reported by DNs as being efficient and effective in organising care a short notice.

In 2001 FSS was absorbed into the intermediate care service (ICS). ICS includes two other services: 'Fast Response', a service to enable patients to remain at home if social support can achieve this and 'Hospital at Home' which provides practical nursing care for patients who have been recently discharged from hospital or whose illness can be managed at home with extra help, for instance a patient with a chest infection. The Hospital at Home service focuses on enhancing and maintaining a patient's independence and is led by rehabilitation professionals (e.g. OTs and PTs). Since Fast Response and Hospital at Home employ HCAs to care for patients in their homes it was felt that FSS could be efficiently managed if it merged into ICS.

On amalgamation FSS changed from a small service with a few HCAs to being part of an organisation with around 60 HCAs with agency staff used to provide care when insufficient employed HCAs are available. The ICS management were keen to remove the distinction between services, so that HCAs could be utilized wherever they were needed. This has led to the concept of a generic HCA in ICS all of whom have the title 'rehabilitation support worker.'

This change has been problematic leading HCAs within FSS to feel that their skills in caring for palliative patients have not been recognised and valued, and they have not had the support necessary to develop and maintain their skills as a result of this lack of recognition. This seems to reflect the literature which describes HCAs as an 'invisible' workforce.

6.4.1 Early stages of the project

Following the request to develop home respite services for the city, we embarked on a study with three phases (Figure 6-1). These are very briefly described in this section to illustrate the context of the study into HCA experiences, which is presented in this chapter.

Initially a survey was conducted of referrals to FSS in 2002, which I undertook with a SHO from the public health department.⁷ The named DN for each patient was contacted with a questionnaire about their experiences of the FSS for that patient. For 95% of the 76/151 (59.6%) replies received the service had been easy or very easy to organise for the patient and for 92% its quality was reported as good or excellent.

Following the survey, between November 2003 and January 2004, key informant interviews with three senior DNs and two discharge co-ordinators⁸ were undertaken to explore issues around sitting services within the city. I conducted the DN interviews and a Macmillan nurse conducted the discharge co-ordinator interviews. A strong consensus emerged that the HCAs in FSS provide a very valuable service, however problems could arise when agency staff were utilized because no PCT employed HCAs were available. From these interviews and as a result of discussions with managers and within the team the decision was taken to establish a home care facilitator (HCF) post to provide educational support and development for HCAs in FSS.

Funding for this post was secured from the local cancer network palliative care strategy group in May 2004. The main functions of the HCF were explored in a stakeholder focus group in September 2004 which enabled a decision to be taken on this issue before a job description was written. Whilst the HCF post was advertised in the national press, a Macmillan nurse from the community team was appointed to the HCF in a secondment position in December 2004.

⁷ The SHO had previously worked with me at the hospice and was familiar with palliative care issues.

⁸ These are the two groups which most frequently access FSS on behalf of patients.

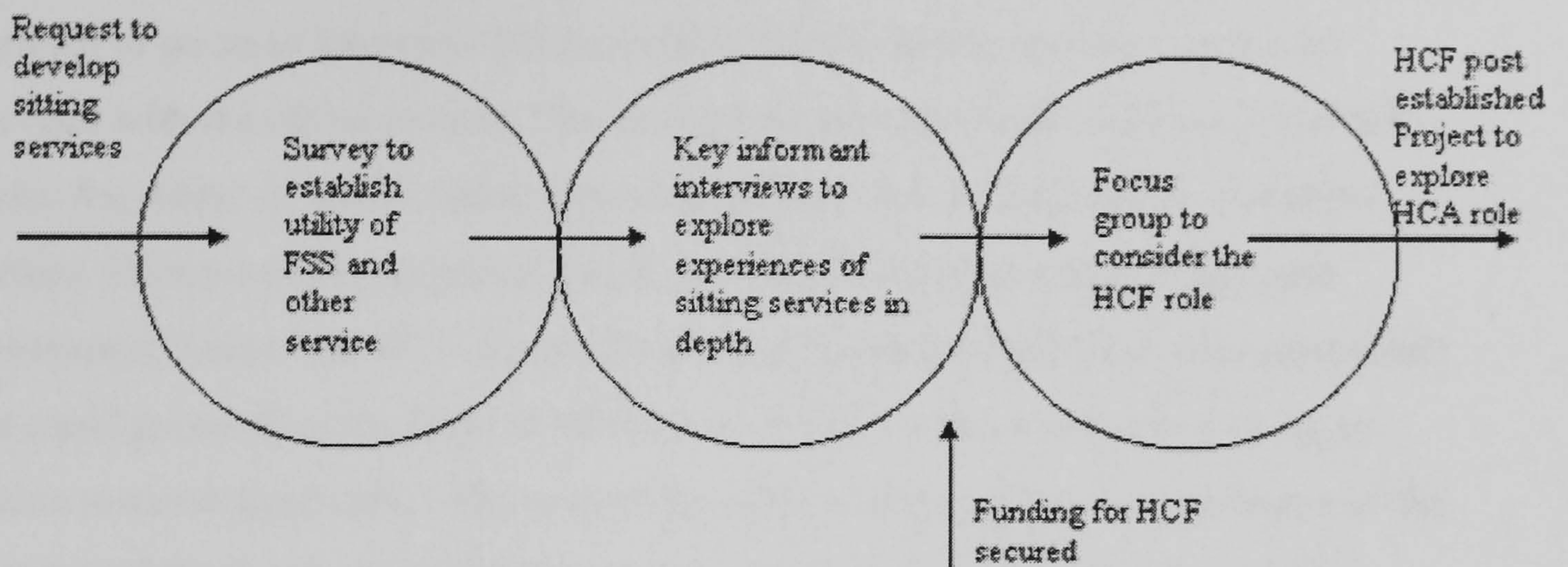


Figure 6-1 - Three phases of research

The early part of the process had raised three important issues around conducting the research. Firstly, HCAs were not represented in the stakeholder focus group, despite apparently having been invited to attend by the lead nurse in ICS. The reason for non attendance was unclear, although it seemed from comments made by both the lead nurse and a discharge coordinator from ICS that it was difficult to get HCAs to attend meetings. Later in the action research group and the interviews the level of antagonism the HCAs held towards ICS was high and many HCAs felt that meetings were not helpful to them. This raises the issue of power within organisations and the difficulty of ensuring that the process of action research is empowering to those with little organisational power such as HCAs. Secondly, the senior manager was keen for the service to develop more rapidly than it was. This illustrates the tension between research, which needs to be methodical and reflective and the pragmatic considerations of service development where speed might be an important factor. These issues were explored and presented in an oral presentation at the 9th European Association for Palliative Care (EAPC) Congress in Aachen, Germany in April 2005 (see Appendix 3.1 page 325).

6.4.2 Ethical issues

Complex ethical issues arose through this project. In January 2004 I wrote to the chairman of the local ethics committee explaining our plans to develop palliative

care services using an action research approach and that our first project was to investigate the development of home care respite services for palliative care patients. Explaining that this involved interviewing key informants within the city and that we planned to go on to interview HCAs, I asked for his advice on how we should proceed with the ethics process. His assessment was that what I had described fell under the rubric of 'audit' rather than research and did not feel able to comment further. I discussed the project at length with the clinical governance/ research governance lead of the PCT, a consultant in public health medicine, who agreed that we could proceed on the basis of this being service development, albeit using an action research approach. I also sought the advice of my research supervisor and the director of post graduate research degrees in the Centre for Primary Health Care Studies, who considered the arrangements to be acceptable.

We conducted the whole of the study using standard information and consent procedures and anonymised data as far as possible, although complete anonymity is not possible for positions in which there is only one post holder, e.g. lead nurse for a specific service. Where it has not been necessary to identify the role of the respondent, I have not done so and where there appears to be a possible breach of confidentiality I have sought the permission of the respondent to use the quote or data which could be identified with them.

We discussed any ethical issues arising as a research team before deciding on which course of action to take. When issues arose which needed to be reported to managers (e.g. lack of safety in their work for HCAs), we sought the permission of the respondents, or the action research group to do this.

6.5 Exploring HCA experiences in caring for palliative care patients at home

In January 2005, one month after the appointment of the HCF, we were able to embark on developing a support and training system for HCAs. We wanted to explore the HCAs' role and experiences in delivering care and to involve them in developing the support system. Whilst we considered using an action research approach was the best way of achieving these objectives, we realised that for organisational reasons it would not be possible to have a large number of HCAs involved in group work, but it would be necessary to explore the experiences of a wider group of HCAs. Therefore as well as establishing an action research group, we

also planned to conduct semi-structured interviews with a sample of HCAs who were not involved in the group. The HCF worked with a research fellow (RF) seconded from the local university for the action research project. Together they conducted the interviews with HCAs and key informant interviews with management staff. In addition they observed meetings in ICS which HCAs attended.

The results I present will mainly relate to the interviews undertaken with HCAs, however, rich data emerged from all parts of this project which informed development of the interview schedule and which was used in triangulation with the data emerging from the interviews.

6.6 Aims

The aim of the project was to:

- 1) Explore the role of the HCA in providing care to palliative patients in the community.
- 2) Explore the experiences of HCAs in providing this care, including the factors which enabled and frustrated the provision of care.
- 3) Explore the training HCAs had already received and what training they felt they needed to fulfil their role.
- 4) Discover the formal and informal support HCAs received in their work.
- 5) Explore HCA relationships with patients and carers and with other health care professionals.
- 6) Consider how a training and support system could be effectively established with HCAs taking a central role in developing such a system.

6.7 Methods

In this section I will describe the methods used in the interviews with HCAs, however initially I will describe the action research groups which had a central role in the development of the interview process and schedule.

6.7.1 Action research group role in developing the method

There were two principal aims of the action research groups:

- 1) To explore the issues presented by the project aims in an interactive fashion with a group of HCAs and professionals who work closely with them.
- 2) To establish a reference group which would reflect on the issues emerging from the research, would take a central role in developing the research question as the project progressed, to focus on developing the system of support and education for the HCAs and to take part in writing up the project and disseminating results.

We were restricted in the number of HCAs who could attend the group, since it was important that the sessions were undertaken in work time. In negotiation with ICS it was agreed that two HCAs could be funded to attend, with meetings taking place monthly. We invited one DN and Macmillan nurse⁹, to take part since these professionals (particularly DNs) worked closely with HCAs giving them clinical support.

Two HCAs.

District nurse.

Macmillan nurse.

Home care facilitator.

Principal investigator – consultant in palliative medicine.

Research fellow.

Box 6-3 Action Research Group Membership

My role was to lead the groups initially, but pass this onto the HCF when she had gained confidence in running an action research group. The researcher fellow's role was to assist in group facilitation including note taking and to develop a working relationship with the HCF. The membership of the group is given in Box 6-3.

We considered carefully how the make up of the group could affect its functioning especially from inequalities in power between members. The ICS lead nurse selected two HCAs who she felt would be keen to participate and would not feel inhibited by

⁹ The Macmillan nurse had been a DN until 18 months previously and was co-researcher with me in the key informant interviews and also took part in the stakeholder focus group. Later she was involved as co-researcher in the critical incident study presented in Appendix 2.

other group members. The Macmillan nurse suggested the particular DN who participated as someone interested in this type of project who she felt would have the confidence of the HCAs. On several occasions we explored with the group whether there should be participation from ICS management. This was strongly opposed by the HCAs who felt that this would inhibit their input.

DNs do give clinical support and a sense of security especially those on call at night.

HCAs spend long hours with patients and notice clinical problems, however their insights tend to be ignored by trained staff.

It is sometimes difficult to provide care going 'by the rules'; families often have their own way of doing things and the HCA needs to fit in.

Some families can be unpleasant to HCAs or they find problems with relationships which they need to report, e.g. husband abusing wife.

They don't have anyone to support them if a bad death or other emotionally difficult thing happens; they just have to cope with it.

Great concern with agency staff: poorly trained, don't interact with family and poor practice which gives FSS a bad name.

ICS managers are not interested in their concerns and nothing changes as a result.

Box 6-4 – HCA themes emerging in first action research meeting

The action research group met on six occasions between January and September 2005. Fears about non-participation of the HCAs did not materialise. In the first group their experiences were recounted very strongly (Box 6-4). These themes were generally recurrent in all of the action research groups revealing high levels of dissatisfaction with the service, particularly grounded in the perception that management did not take HCA concerns seriously, did not support HCAs and did not address the poor working standards of agency staff. These issues were explored at length by the group who understood that many needed to be addressed before an effective education and support system could be developed. The HCF addressed these issues with management as part of her official role in providing support for HCAs.

The group enabled reflection on issues which were emerging as the HCF and RF attended meetings in ICS and interviewed key informants there. The group took part in developing the presentation for the EAPC Congress 2005, although the abstract had been submitted before the group formed. In addition issues emerging in the group enabled the guide for the interviews with HCAs to be developed.

The last meeting of the action research group took place in September 2005. Following this a major reorganisation in FSS took place leading to a lack of clarity over the position of the service, which has yet to be resolved. In addition one of the HCAs in the group left the employment of the PCT. After discussion with senior managers it was decided to wait until the new structures were in place before reconvening action research groups. Unfortunately, subsequent financial problems in the PCT have delayed reorganisation preventing any further action research work to be undertaken.

6.7.2 Interviews

The purpose of the interviews was twofold: to gain insight into the HCA role and experience to enable the development of an education and support system, and to generate new research insights for publication. The interviews were undertaken by the HCF and RF together to enable these two aspects to be addressed effectively; the HCF had considerable clinical experience but no previous experience in conducting research interviews, whilst the RF had research but no clinical experience. The interviews were undertaken in August – October 2005, six months into the project. It was agreed before the interviews were conducted that I would analyse the interviews and my involvement was explained to the participants at the outset of the interviews. After completing the interviews the HCF and RF were to have developed the action research further concentrating on the support and education system, which would constitute the action research intervention with the insights from the interviews informing this process.

6.7.2.1 Interview sample selection

Fifteen HCAs were purposively sampled through discussion between the HCF, RF and lead nurse in ICS. HCAs with a range of experience were recruited with attention to: length of employment, i.e. from a few months to several years; work patterns i.e. day or night shifts; employment contract, i.e. bank or on permanent contracts and

apparent work preference, i.e. main role in FSS or working occasional FSS shifts but mostly employed in Hospital at Home or Fast Response. It was hoped that 15 interviews would enable saturation to be achieved since this could be combined with data from the HCA narrative within the action research group; however further recruitment could have been undertaken if necessary. Only PCT employees were selected as the aim was to develop PCT rather than agency services at that time.

6.7.2.2 Interview process

Initial letters were sent to the HCAs by the HCF inviting them to be interviewed (Appendix 3.2 page 326) followed by a telephone call from the HCF. Full written information was given to HCAs (Appendix 3.3 page 327) and signed consent was taken. The voluntary nature of the interviews was stressed both in written information and verbally by the HCF. Interviews were conducted at the HCA's home or in the palliative care team offices, at the convenience of the HCA. HCAs were able to claim the time spent in the interviews as work time. The interviews were audio recorded on an Olympus DM 10 voice recorder and downloaded onto computer for transcription.

6.7.2.3 Interview guide

The interview process was discussed in action research meetings with suggestions being made for areas of questioning. The interview guide was developed in a series of meetings between HCF, RF and me, during which we discussed the data emerging from the action research group, key informant interviews and observed meetings (Appendix 3.4 page 330). Key areas for questioning were identified with notes to prompt questioning into important areas. The HCA was asked to recount critical incidents which could illustrate the nature of their work and particularly incidents which illustrated how they handled difficult situations.

6.7.2.4 Ensuring reliability and validity in the interviews

Interview transcripts were read and checked by both the RF and me. I did the formal analysis and discussed the emerging themes with the RF and HCF. Disconfirming examples were sought, especially those which challenged the strong themes which emerged from the action research meetings. Considerable data available from the key informant interviews, focus group and action research groups allowed triangulation to be undertaken. Plans to explore the emerging themes in the action research group

were not realised as the group ceased to function, however this chapter was read and commented on by the HCF.

6.1.1 Analysis

The analysis of the interviews fell within the overall analytical framework for the project as represented in Figure 6-2. Throughout the project two interlinking but distinct approaches were taken. A practical or pragmatic approach whereby the research team, but principally the HCF utilized emerging themes for developing ideas for education and support in reflection with the action research group and colleagues, and a more formal approach where interviews were coded and interpreted using a realist theoretical approach. A dialectical process was maintained between these approaches with theoretical analysis informing the developments and data emerging from developments being used reflectively in the theoretical analysis.

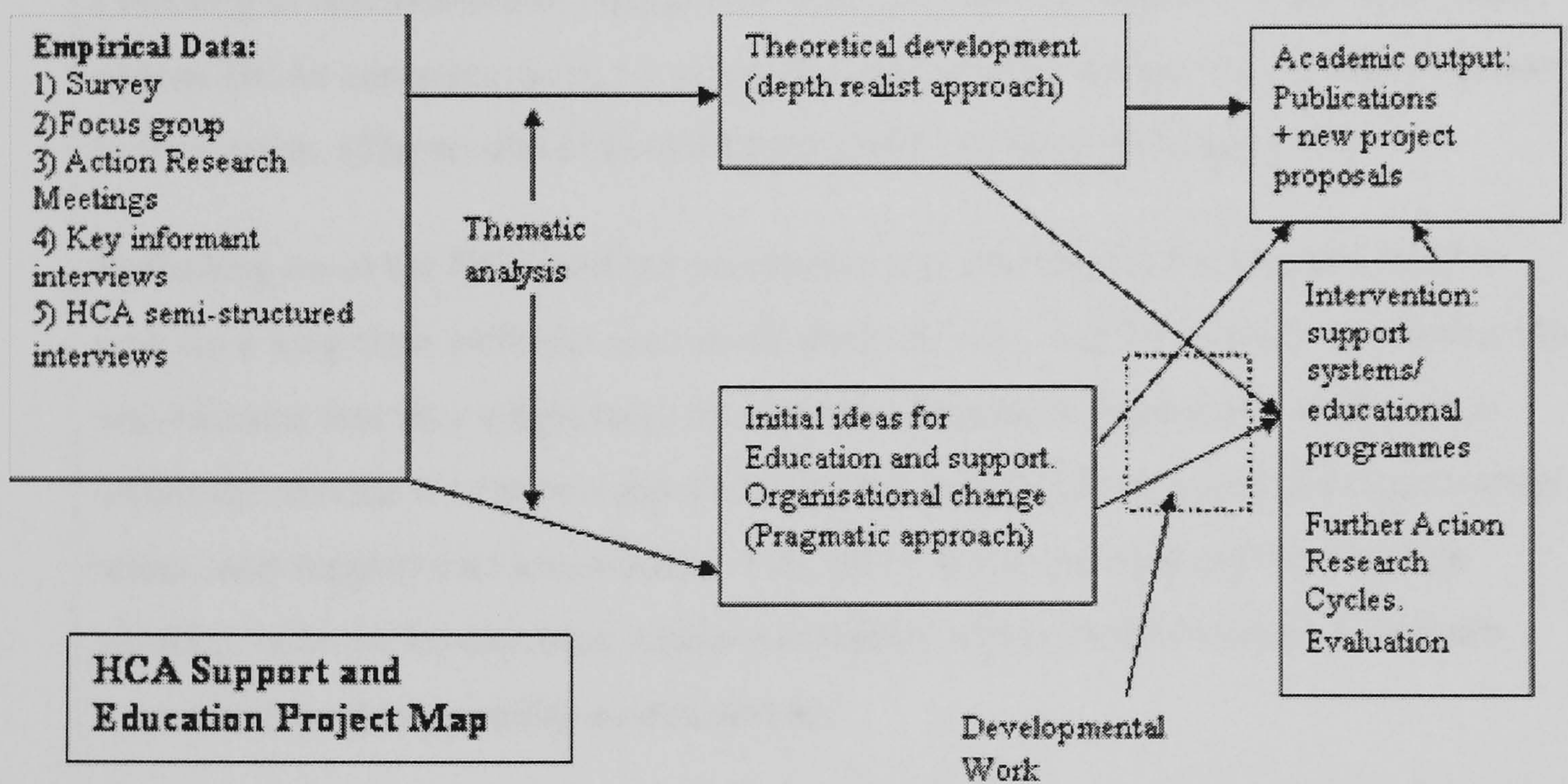


Figure 6-2 - Analytical framework for HCA support and education project

During the project I held regular meetings with the home care facilitator (HCF) and research fellow (RF) during which we reflected on the emerging data and our interpretations of it. Exploring the data and wider context together, from three perspectives – namely, experienced palliative care CNS, social science researcher and palliative medicine specialist enabled a reflexive process which enhanced our understanding of the depth of the issues emerging. This had the additional benefit of

On 27.06.05 during a research meeting, whilst discussing the data emerging from action research meetings and key informant interviews which were being undertaken by the HCF and RF, the three of us discussed the pride that HCAs take in their role and the distress they feel when agency staff do not care for patients with the same diligence. Drawing on this data, the HCF reflected on how HCAs' concerns were broader than issues relating to individual patients, as they also felt that the poor care delivered by agency staff reflected on the service, giving it a bad name. She commented that the HCAs were very proud of the service they delivered, similar to the pride which she had felt as a nurse in the services in which she worked.

Following this, the RF reflected how it was interesting that some agency staff had been recruited to PCT HCA posts; to which the HCF commented that this might be the case but she felt that they did not stay in post for long.

Listening to this discussion I suggested that we needed to explore in the interviews: a) how HCAs came into post, b) where they had worked before and c) why they stay in their posts. (The results of a) and b) are given in Figure 6-3 page 258).

Reflecting on c) the HCF said her perception was that the HCAs who had been in post for a long time were the ones more likely to stay. The RF wondered whether this was because that they might have received the formative experience of their role whilst the service was more supportive and this enabled them to remain in post even when such support was less evident. This led to a discussion about the possible parallels with the loyalty seen within companies which enable workers to remain even when working conditions deteriorate.

In our exploration of these issues in subsequent interviews, we found that HCAs had a strong sense of vocational commitment to the patients through the service *they* provided rather than loyalty to their employers i.e. the PCT (for example see the quotes in Box 6-13 - Job satisfaction for HCAs, page 277).

Box 6-4a Example of discussion between the members of the research team (an experienced palliative care CNS, a social science researcher and a palliative medicine specialist) showing how each individual contributed to the reflexive process, how this process suggested new lines of enquiry for the interviews and how it enhanced the team's understanding of the depth of the issues emerging.

Note: This account is a summary written directly from the audio recording of the research team meeting.

broadening each team members' conceptual understanding (see Box 6-4a page 256a for an example of this process).

I listened to the interviews on three occasions, first to check the transcripts and on two further occasions to immerse myself in the data. Following this I coded the interview texts using a template method (King, 2004; Crabtree and Miller, 1999). The interview guide was used as the basic template and this developed during the course of the analysis. The codes for emotional labour were added to the template at the outset of the coding. This theoretical concept was incorporated into the study after the interviews had been completed following discussion of the emerging themes in a university research group. I had previously not been aware of the work on emotional labour. Substantial developments were made to the coding structure whilst coding the first two interviews and only minor adjustments following this.

I discovered that attaching codes relating to Layder's domains led to multiple coding of single texts into several domains, illustrating how these represent a high level of abstraction and the complex interaction of individual domains. Therefore to code for domains I examined prolonged narrative sections of text which described scenarios in detail. I was then able to return to the coded text to look for similar and conflicting examples.

Using the coding framework also did not enable individual approaches to emotional labour to emerge. I therefore extracted all of the coded text for emotional labour for each participant and reconstructed a text summarising the key themes for each individual.

6.7.4 Presenting the results

This thesis is the first in depth presentation of the results emerging from the interviews or action research groups. However, a report was prepared for the PCT by the HCF and me highlighting the issues relating to HCA support and safety which we considered required urgent attention. In addition, an oral presentation concentrating on the data emerging from the action research groups was presented at the International Practitioner Research/Collaborative Action Research Network Conference, Utrecht, Netherlands, November 2005.

6.8 Results

Fifteen interviews ranging between 37 minutes and 1 hour 32 minutes were undertaken. All HCAs answered a list of standard questions at the outset, the results of which are given in Figure 6-3. This shows a spread of HCAs in terms of employment contract (bank or permanent) and working patterns, i.e. day and night shifts worked.

Number of years in post	Total number of years experience	Gender	Employment contract	Shifts worked	Family Support	Hospital at home	Fast Response	Grade	Previous HCA/NA location	NVQ level attained
0.4	15	F	Both	Day	Yes	Yes	Yes	B	Combination	2
0.5	29	F	Permanent	Night	Yes	No	Yes	B	Hospital	0
1.4	4.5	F	Both	Both	Yes	Yes	Yes	B	Combination	0
6	23	F	Bank	Day	Yes	No	Yes	B	Combination	2
8	10	M	Both	Day	Yes	No	No	B	Combination	0
11	24	F	Bank	Both	Yes	No	Occasional	B	Combination	2
11	23	F	Both	Day	Yes	Occasional	Yes	B	Community	0
12	12	F	Bank	Both	Yes	No	Yes	B	None	0
12	12	F	Bank	Both	Yes	No	Yes	B	None	2
12	15	F	Bank	Day	Yes	No	Yes	B	Community	0
13	14	F	Bank	Night	Yes	No	Yes	B	Nursing Home	0
14	14	F	Bank	Night	Yes	No	Yes	B	None	2
14	17	F	Bank	Night	Yes	No	No	B	Community	0

Figure 6-3 Profiles of HCAs interviewed (one profile mislaid)

The majority of HCAs had worked for more than 10 years and only three commenced work for FSS since the move to ICS. Only one HCA who had worked for FSS before this time did not compare the experience under ICS unfavourably with the previous arrangements. Only one HCA had less than 10 years experience in the HCA or NA grade and most had worked in other settings, many in a combination of community, hospital or nursing home. Whilst ages were not recorded, several HCAs spoke about working on the bank in semi-retirement. For many it provided work when they wanted it so that they could look after grandchildren or go away for long breaks.¹⁰ A minority had NVQ qualifications and few when asked were keen on pursuing NVQ.

6.8.1 Factors contingent on the HCAs role: space, relationships and tasks

These interviews provide a rich insight into the HCAs' role working as 'sitters' for palliative care patients in the community. Our findings build on those of Ferguson et al. (1998), who in their study of the Macmillan carers scheme noted that:

¹⁰ Bank work also emerged as a method of maintaining control over their work against a 'bullying' management style.

‘Three key issues emerged; the difference between the role of the qualified and unqualified nurse; the nature of the health and social care divide; differences between formal and informal care. Macmillan Carers find themselves working at the intersection of these three areas, with considerable implications for their daily practice’ p7.

I go to the patient’s house, we stay with the patients for five hours. We do all the personal care – hygiene, meals, whatever needs to be done for the patient. Make sure they are safe for the five hours that we’re there (*HCA L*).

Well my primary concern is the patient you know it’s all according where they’ve got it [cancer] and I will do the catheters and if there’s colostomies you know, do the colostomies, do the oral care and everything, make sure that they have plenty to drink. If they’re on drivers, make sure that’s okay. You know, everything going ok..... Generally looking after the patients and the family (*HCA B*).

[Your] responsibility is to your patient and his carers in their own home... And you have to be very sensitive to their needs, and what they want (*HCA H*).

They [family] say ‘no, you know, I’ll feed them’. And medication, obviously, they do, because we’re not allowed to do medication, so that’s always a good thing if they do do the medication. But I think often it’s the feeding, or sometimes they just want to sit with them. I mean, if they’re dying, you know, they just want the family there, and you kind of stand back, but you’ve always got to let them know that you’re there for anything that they do need you for (*HCA I*).

Box 6-5 - HCAs poorly defined and negotiated role

HCAs perform tasks on the boundary between health and social care although these are not clearly defined. The HCA often had to negotiate these with the patient or family when they arrived at the home (Box 6-5).

From these extracts it is apparent that there are three important areas in the HCAs’ role: – spaces, relationships and tasks (Table 6-1). The space in which the HCA works, the patient’s home, was likened by one HCA to a castle which she entered with reverence having said a prayer, although she was not religious. HCAs had to respect the families’ way of doing things (Box 6-5) even if they found it strange or unpleasant at times. In this setting the HCA was isolated and this could lead to

difficulties in coping with caring situations which needed assistance (Box 6-7 page 262).

SPACE	RELATIONSHIPS	TASKS
<p>Patient's Home Sacred space Cultural norms Place of multiple dramas Relatively un-modifiable Issues of personal safety</p> <p>Isolation Issues of personal safety Lack of clinical support Being "in charge" Loneliness Dealing with crisis, death</p> <p>Uncontrolled clinical environment Clinical tasks performed in "substandard conditions" e.g. lifting and handling, drug storage / administration poorly controlled Hazards associated, e.g. oxygen, fire</p>	<p>With patient Built up over time On patient's terms Supportive and reassuring</p> <p>With relatives Built over time Negotiated Supportive and reassuring Protecting from overwork "Relative as patient" Management of conflict</p> <p>With peers Supportive FSS HCA informal network Conflictual (with agency) Hand over to encourage continuity Setting precedents: working to avoid them</p> <p>With Supervising clinical staff Availability Support – clinical, professional and emotional Lack of respect</p> <p>With Managers Conflict Lack of named manager Lack of respect Lack of action to concerns Little understanding of their role Conflicting priorities – palliative vs rehab Contractual issues</p>	<p>Domestic Not in job descriptions – but do it anyway Boundaries are unclear For patient not relative</p> <p>Clinical Surveillance Decision making Dealing with emergencies</p> <p>Physical Catheters Lifting Toileting Hygiene Monitoring pain "Assisting" taking medication</p> <p>Psychological Active listening Supporting Passing on issues</p> <p>Social Mobility Nutrition – preparing food Ensuring safety Assisting family Family surveillance</p> <p>Emotional labour Coping with feelings Projecting affect Empathising Supporting dying Ontological security Emotional Gift Promoting continuity</p>

Table 6-1 - Contingent factors in HCA Role

The isolation could also put the HCA at risk for instance from confused or violent patients or relatives and from physical dangers (Box 6-6). Several HCAs were

concerned because the management did not take these issues seriously in their view.¹¹

No, it's getting slightly better now but there is a lot of things out there that aren't safe, I had Carbon Monoxide poisoning three years ago and ended up at the poisons unit at [major city] and from that moment on I've been fighting and I still am now with [manager] to get Carbon Monoxide testers for the staff, no. Mobile phones aren't provided I mean this isn't just me all sorts of things have happened to other girls. There were three of us that ended up with Carbon Monoxide poisoning. Three members of staff (*HCA J*).

(*Regarding mobile phones*)....And I know it's cost, and I know it's... it's headaches for everybody, and I appreciate all of that, but if I... some patients, if you don't turn up at eleven o'clock at night, they'll think 'they've blooming left me again tonight, and that agency staff or something hasn't turned up – God, how am I going to cope with John?' But they cope. But I could be outside lying under my car, and... my husband wouldn't know about it, not until four o'clock the next evening, and he could probably think, 'oh, she's gone down the shops now'. So, by the time anybody noticed I hadn't turned up for shift...(HCA A).

... I left the premises because the son was drinking, very drunk, and banging on the door and that to come in. And I wasn't... you know, I was worried, so I left the premises, and I filled in an incident form about that. But all I did was hand them in to the office – finished! I never heard nothing. Never, never came back (*HCA F*).

Box 6-6 - Isolation and Lack of Safety

It is important to note the complex interaction between categories in Table 6-1 that are in evidence. The tasks which the HCA performs on behalf of the patient are in the isolation of the patient's home, will be affected by the relationships which the HCA has with the patient and family and will be affected by other tasks which the HCA has to perform. The extract in Box 6-7 is given by way of example.

¹¹ These were issues which the HCF and I dealt with directly with managers in the PCT and in the report.

I went into one lady....you'll sack me...this lady wanted to go to the toilet, oh dear, she was crying she wanted to go to the toilet, and I kept saying "just do it in the bed I don't mind clearing it". She said "I'm not going to the toilet in the bed," I said "well I can get Late Call out but they won't be here". She said "I've got to go, I've got to go"..... and she was crying and Late Call probably couldn't get to me for half an hour.... so I went in the kitchen and opened the cupboards and I looked through and there was a very shallow dish and I came out with this dish, I said "I could put....", "yes please" she said and I pushed it under, because it's one of these soft feather beds and I got it under quite easy and she went, and she kept saying "oh thank you, thank you, thank you" she said "I wanted to go so badly" and she wouldn't do it in the bed. I mean you shouldn't do that should you with a shallow dish it's not a bed pan but¹²..... (HCA N).

Box 6-7 - Complex interaction of contingent factors

In the isolation of the patient's house the HCA was precluded from safe lifting of the patient, so toileting had to be achieved by some other means. The isolation also meant that the clinical facilities such as a bed pan were not available. Clinical support was available but the DNs in Late Call (evening and night time district nursing service) were not close by and not able to attend immediately. The HCA was charged with finding a solution to the patient's need for toileting. One possible solution was for the patient to toilet in the bed and for the HCA to change the patient following this. However, this course of action was not acceptable to the patient even with the reassurance of the HCA. If the guidelines had been followed there may well have been no option other than to hope the patient was able to 'hold on' until the Late Call nurse could arrive. However, the HCA was able to empathise with the patient and found a solution which was acceptable to both, but possibly not to the HCA's employer or supervising Late Call nurse. The HCA was clearly aware that she was 'breaking rules' and could be reprimanded, but in the immediacy of the situation she made a judgement, that the shallow dish could be used as a bed pan and that she could safely do so. The effect of her actions enhanced her relationship with the patient who was very grateful. If the outcome had not been satisfactory and the

¹² HCAs often used conjunctions 'but...', 'so....', 'and.....' etc at the end of descriptions particularly if the issue raised questions or illustrated dilemmas or conundrums. This is a colloquial device which I have subsequently noticed is regularly used in this locality.

patient had been injured by the HCA's actions, then her relationship with the Late Call nurses or her managers may well have been adversely affected.

Thus the HCA in this example elevated the patient's emotional needs over the 'rules' with some risk to her professional position. This illustrates the importance of emotional labour in supporting the patient and family, considered further in Section 6.8.3.

6.8.2 Social settings and the HCA

It is useful to re-examine the space, tasks and relationships of the HCAs work in terms of Layder's domain of 'social settings' (Layder, 1997). The home of the terminally ill patient and their family is the geographical space in which HCAs work. Up until the time of arrival of the HCA the space is the patient and family's home, but after she arrives it also becomes a work space for the HCA. The home/work, private/public divide is a significant aspect of palliative care. Most patients wish to stay in their homes when they are dying (Higginson and Sen-Gupta, 2000), however this is often not achieved (Gomes and Higginson, 2006). Early inpatient hospices tried to emulate the home environment for patients (James, 1992), similarly maternity units take steps to provide a 'home like environment' p4 (Kirkham, 2003) for deliveries. In the patient's home the reverse process is apparent with various degrees of transformation into a clinical environment.¹³ Peace has explored in detail the issues around caring in the client's home, exploring the interface between the *private* and the *public* (Peace, 1998). Home is normally private, particularly in the context of the British society in the early 21st century and HCAs are well aware of this:

R: I know nothing about them. I'm going into their home, that's their castle
(HCA F).

However when health and social carers enter the home the private space becomes increasingly public. The HCA has no right of access to the home, except as a public employee where she is contracted and paid to work by the PCT. Entry requires negotiation by the DN who arranged for FSS and by the HCA when she arrives.

¹³ In my clinical experience the extent to which the home resembles a clinical environment varies greatly. In some situations there is little in the way of clinical equipment in the home. At other times the patient's room almost resembles an inpatient unit with a hospital bed, commode, hoist and clinical equipment filling the whole space.

In addition to the ‘ambiguity’ of the geographical space, there is an ambiguity of the HCA’s caring role which in itself partly emerges from the ambiguity of space. Davies (1998) provides a useful theoretical model to explore this role ambiguity, identifying three types of care work:

- Caring – provided by a network of friends and family.
- Carework - low paid and typically performed by women.
- Professional caring - based on scientific and thorough training.

Caring is informal work which takes place in the private social setting both in terms of geographical space and relationships. Formal contractual agreements and payment do not normally operate in this type of caring, although informal responsibilities and rewards might be evident. ‘Caring’ is marked by a relative lack of division of labour with relatives and friends engaging in all types of caring work, personal care, cooking, cleaning, shopping etc. Conversely within a care institution such as a hospice, caring work is marked by a division of labour, e.g. nursing, kitchen, laundry, cleaning etc (James, 1992).

Carework is low paid, low status work, including: home-helps, child minders and other domestic servants. Carework falls outside of any sustained training framework and there is a ‘blindness’ to the skill base which these workers possess (Davies, 1998). Davies highlights that home-helps frequently build up a relationship with their clients, a feature they might enjoy and see as being integral to their work, although this does ‘not strictly “make sense” in the public sphere [of paid work] in which they operate’ p131 (ibid). This has a resonance with the HCAs in FSS who are located within the ‘carework’ group.

Professional caring engaged in by registered nurses conversely involves specialist knowledge acquired through a formal training process. Whilst the boundaries of professional caring, as Davies argues are often indistinct, I would suggest that for the work of a DN, boundaries are more distinct than those of HCAs.

HCAs perform ‘carework’ in terms of their status, training and remuneration; however its boundaries blur into both ‘caring’ and ‘professional caring’. It is apparent from the interviews that HCAs engage in care *alongside* informal carers in the home. Thus the HCAs’ work will blend in with that of the family in caring for the

patient, supporting them where necessary, an aspect suggested by the name ‘family support’. Occupying this role influences the relationships which the HCA develop with patients and families as illustrated by the descriptions of being like family or like friends.

We just plod on like, we’re just part of their family and we’re there to help and support and care for them (*HCA C*).

[I] introduce myself to the family, really just to give them the feeling of I’m there as a friend I’m there to support them (*HCA F*).

With the indistinct nature of her role the HCA needs to make frequent decisions about whether specific work is appropriate. Should they clean the kitchen, vacuum the floor, take the dog out, do some shopping for the patient?¹⁴ It seems inherent within the role, that supporting the family will not have clear boundaries, just as with ‘caring’ by family and friends there is an inherent lack of division of labour.

Whilst there is overlap between the ‘carework’ they officially perform and informal ‘caring’, there is also overlap with ‘professional caring’. Part of their role is to monitor the patient’s clinical condition, be aware of the issues around clinical equipment such as syringe drivers, catheters etc and effectively manage changes and problems arising – through calling the DN or performing simple clinical tasks themselves. In addition their supportive role extends to emotional support (see Section 6.8.3). This is apparent in the interview extract from the manager who set up FSS (Box 6-8).

¹⁴ This blurred role is an area of contention with some in senior management. “I don’t pay them to walk the dog” (Quote from a manager).

So I think, I mean [HCAs] do need to be able to manage people at end of life so they need all those basic nursing skills so they are able to make patients comfortable and understand and it's all the stuff around 'essence of care' really that you would want them. They have to be aware of syringe drivers, they have to know about symptom management, not necessarily a level of detail but they need an awareness. They need to know about the services that are around for them to call on and support them erm, if they're in trouble. They also need sort of skills in terms of talking to families, they're there for a long, long periods of time there're going to have people talking to them, opening up to them because they're there and they are developing a relationship with them so its skill around counselling, confidentiality, boundaries, you know it really is quite a complex role when you start to unpick it isn't it?
(*Manager 01*).

Box 6-8 The complex role of the HCA

The 'social setting' for HCA work is therefore *not* the same as for DN work although the geographical space of the home is identical. The DN, offering professional care, comes to visit the patient for a brief period and is more likely than the HCA to transform the patient's home from a private to a clinical space. Thus the social setting occupied by the DN in relation to the patient and family is defined by the DN's clinical role, relationships marked by professional distance and the relatively short time they spend in the home. The social setting for the HCA falls in the ambiguous space between private and public and between types of caring role, complicated by 'blindness' to the complexity of her work setting and its implications. Given the ambiguity of the space and roles the exact nature of the social setting for the HCA is not clearly defined until a period of negotiation between the patient, family and carer has taken place. HCAs use their experience to negotiate this smoothly.

'I mean, you can usually tell. Sometimes they'll say, "well, you know, you stay in the bedroom and if you need me, we'll be downstairs, if you want any help", and you do whatever for the patient – whatever they need – while you're there. But, um, on the other hand, you might go in and they'll say, "you stay downstairs and we'll call you if we need you", and you kind of stand back. But I just say,

“well, you know I’m here, and for whatever you need me, just call me”, and you know... whatever is needed’ (*HCA I*).

The ambiguity of the social setting can lead to misunderstanding by the patient or family as to what the HCAs role should be.¹⁵

‘I was in the kitchen washing the patient’s plate and cup up and the daughter come and brought her and her husband’s plates and that and she said “here you are” and she said, “well then you can do my washing up” and I said “yeah”..... and you know I just walked out of the kitchen and went back to the patient. I didn’t say anything to her I just bit my tongue and.....’ (*HCA B*).

Patients and their carers might resent their home being transformed into a clinical setting and the intrusion this involves, with many different carers coming in and out. This issue emerged during an interview with a carer of a patient in the emergency admission study (Section 5.4.4.2 – Box 5-2c page 197) and has been previously highlighted by Grande et al. (1997b). Many HCAs were aware of this citing it as a major reason for their efforts in trying to maintain continuity of care for ‘their’ patients and families.

Layder (1997) points out that social settings are recognisable by the reproduced social practices inherent in them through which actors understand the rules which govern activity within that setting. He suggests that in some settings these reproduced structures are more sedimented, e.g. rules of behaviour in parliament are well defined; however in more informal settings the rules are more malleable and emergent social practices will be more apparent, e.g. a family’s practices change over time. There is a degree of malleability in the social settings in which HCAs work, since the rules are not fixed in contractual agreements. However certain rules are apparent which are clearly encoded within social and cultural norms creating a strong discourse of ‘how things should be done’ in the minds of HCAs. The strongest views of HCAs regarding the correct way of behaving were related to issues of emotional labour. This will be considered in the next section.

¹⁵Not infrequently families might be under the impression that HCAs are trained nurses. The uniforms they wear might reinforce this as they are not dissimilar from nursing uniforms.

6.8.3 Emotional labour

Emotional labour is a central feature of the work undertaken by trained nurses and auxiliaries in hospices (James, 1992) and this study has found it to be a fundamental aspect of HCAs work in patients' homes. As with James' hospice nurses, HCAs' work is often a blend of physical and emotional tasks. Box 6-9 illustrates how one HCA uses physical contact including massage (a procedure some HCAs referred to as "creaming") in order to relax and comfort a patient, simultaneously attempting to relieving her distress and relieving her husband from his caring role.

Interviewer (HCF):she's telling you she's frightened what are you doing, what are you saying?

HCA: Talking to her just trying to relax her, I stroke her forehead, I hold her hand, erm I talk to her all the time, you are talking to her but she calls out for her partner she, you know she'll talk to you for a while and then she'll scream for her partner and he'll come in he'll satisfy her just for a minute, he'll go out, she comes back, she's not sleeping at all, she is just constantly awake all the time. Give her drinks, give her whatever she needs, make her comfortable, her legs ache, her feet ache, you rub her legs I mean we are doing that cream and her legs cream and her feet cream and her hands you know, doing anything to make her comfortable, but just constantly for five hours honestly, just talking to her. I just wish, I wish there was some way that she could be at ease and she's not (*HCA D*).

Box 6-9 - Emotional labour - primacy in HCA work

Although similar tasks may be undertaken in an attempt to comfort a patient in the hospice setting rarely would it be possible for a member of staff to *continuously* care for a patient in such a way. The intensity of the suffering which the patient is displaying and the length of time which the HCA is spending have an emotional effect on the HCA who recognises that even her efforts are not bringing ease to the patient's suffering.

6.8.3.1 Primacy of emotional labour

Another feature of emotional labour as undertaken by HCAs in patients' homes distinguishing it from that undertaken in institutions as described by James (1992) and Smith (1992) is its permissible primacy in the home. In the hospital or hospice

clinical tasks and tasks which are designed to ensure the smooth running of the ward have primacy over emotional labour. Emotional labour will frequently be undertaken whilst physical tasks are performed e.g. bathing, dressings etc. Emotional labour as a primary task can be undertaken only when time allows and when 'the work' is done. James illustrates this by giving an example of a hospice nurse talking to a patient and expecting to be told by her peers or supervisors to 'do something' p498 (James, 1992).

In a hospice, the attempt is made to provide patient centred care, in which tasks are performed at a time most appropriate for individual patients (using a model of family rather than institutional care); however in reality work to care for patients' needs are fitted into an organisation schedule. Hospices are therefore more appropriately seen as offering institutional or 'workplace health care' p491 (ibid). Although staff will work hard to try to make the organisational schedule as flexible as possible in order to personalise care for individual patients, this is not always achievable. In contrast in the patient's home the HCA works largely to the patient's timetable and preferences. The HCA is therefore able to allow the patient or the family to direct her work priorities whether they are to help with domestic work or to sit and talk (Box 6-10 *HCA C*).

R: You know, this lady, that's how she wanted to express herself and we have to sit there and listen and that's what we were there for, her support and if that's what she wanted to discuss in that day, if she wanted me to do a load of ironing I'd stand there and do it but if she wanted me not to do nothing, and just sit there and listen to how she felt and if she was frightened then I'd ask, feed it back then I'd ask "why were you frightened?" feed it back and then she'd come out with it and then we'd deal with it (*HCA C*).

R: It's basically just to sit with them and you might just stroke the hand or like I said about this person we massaged her feet with cream and stroked her head, anything that would try and make her comfortable, that's all you can do is make a patient comfortable.....erm, be there, it's being there, isn't it?....and calm (*HCA G*).

Box 6-10 - HCAs: being an emotional presence

Although James (1992) argues organisational factors are at the root of the restriction of emotional labour, the primacy of physical tasks may also enable professional carers in institutional settings to avoid engaging in emotional labour or exposing themselves to difficult emotional situations (Smith, 1992). Allowing the patient or family to take control of the caring agenda potentially removes that protection from the HCA, who is captive in the home for the period of her shift; HCA C in the example in Box 6-10 ‘bawled her eyes out’ on getting to her car having helped plan the patient’s funeral. Ferguson et al. (1998) similarly note the refuge of the HCA’s car at the end of a shift.

HCAAs work 5 – 7 hour shifts when they are in the company of the patient for the whole time. They may be asked to do specific tasks however their presence may be primarily to ‘be with the patient’ giving the patient company and responding to their needs as and when they arise (Box 6-10 *HCA G*).

6.8.3.2 Being there for the patient

‘Being with the patient’ is an active rather than a passive task. Being actively present involves attending to the patient through being aware of their physical and emotional needs, responding appropriately to those needs and remaining alert so that care can be promptly undertaken. Some HCAAs cited instances of HCAAs being passively rather than actively present and these were interpreted as a failure of care. Such instances were exclusively levelled at agency staff.

HCAAs on a night-sit are expected to remain awake so that they can monitor the patient and respond to the need for toileting or other issues. Some HCAAs reported that agency staff had gone to sleep at night and patients had not been able to get the help which they needed¹⁶ (Box 6-11).

¹⁶ Those of us working in the area clinically are also aware of instances where patients have been found wandering out of their houses when HCAAs (reported to be from the agency) have fallen asleep. These issues also emerged in key informant interviews with district nurses.

.... her father used to say, “ring the office” he said “if you send any more [agency] girls” he said just said “just send me a cardboard cut out he said and I’ll sit it in the chair” (HCA.N).

One lady recently said [the agency staff had] been sleeping in her back bedroom on the bed. She said “I called in the night and they didn’t hear me”. I think that is disgusting, you know they are being paid to do a job and if that lady had fallen and if anything had happened you are responsible because you are there to look after that patient so....you’ve got to explain yourself haven’t you? (HCA G).

Box 6-11 - HCA: Failure to be an active presence

The majority of the HCAs interviewed made other comments about how agency staff often failed in their duty of care. These issues included failing to turn up to a shift or arriving late, failing to give an adequate handover, failing to encourage patients to eat or drink, not engaging with them and not attending to hygiene adequately.¹⁷ All of the HCAs we interviewed were proud of the service which they offered to patients and were distressed by the failures of the agency staff. Some did comment that not all agency staff behaved in this way, but their failings were a strong theme which emerged in the interviews and the action research group meetings.

6.8.3.3 Listening to patients; answering their questions

In addition to being there for the patient, HCAs reported that they spent time listening to patient’s stories, especially their fears and problems. It could just be the act of listening whilst the patient unburdened themselves which was effective as the HCA supported the patient:

‘You go and you introduce yourself and within an hour or two they’re talking to you quite openly about their illnesses. Some of the patients have opened up to me in confidence and I know that I would not even repeat to the families but unless I felt that it was a legal matter then obviously but mostly, you know, you just feel that they needed somebody outside that they could feel they could trust to talk to about a simple matter’ (HCA F).

¹⁷ During action research meetings there had been strong criticism of agency staff in these terms. We had especially decided to explore this issue in the interviews in order to see whether it was a general complaint of HCAs.

‘Just learning to relate to people, listening to people and making people comfortable. I think if you can listen because a lot of people like to talk, it unburdens them, if you can do that, you know, and that’s all’ (*HCA O*).

Patients would often express fear of the process of dying or for their family when they had died, but there were many other issues; the HCA needed to be prepared for any question from a patient. One HCA mentioned that sexual issues can be raised, which even for trained staff are considered highly challenging:

‘Just fears of the future.....I mean a lot of people are scared of dying, not just the dying process itself, the people they’re leaving behind....some people want to talk about it, some people don’t..... all sorts of things it’s particularly with the younger people they’re worried about how their other halves are going to survive and the children and sexual things, all sorts of things. It’s just so complex it’s actually allowing somebody the opportunity to talk without forcing them’ (*HCA J*).

Other patients were reported as asking the HCA about their prognosis. For some patients this may represent a chance to speak to someone whom they trust and it may well indicate that patients think that the HCA have more knowledge of their condition than they do. None of the HCAs would answer patients directly, some would reflect the question back onto the patient asking them about their expectation, whilst all would refer the patient onto the DN or GP:

‘If they ask me about their illness, their cancer, how long they’ve got then I don’t answer ‘cause I don’t know, then I’ll ask them, and I’ll say “how do you feel”? I answer it back with a question then I ask them “would you like someone to come in and discuss your illness, you know, the terms and what’s going to happen and where you go from here and how long and what stages you’re going to go through?” and I just ask someone if they want someone in to discuss it with them and if they say “yes” then I contact the appropriate person who is more experienced to come in and explain that rather than me putting myself in a situation that I don’t know anything about’ (*HCA C*).

For all health care practitioners discussing such issues is difficult (Munday et al 2007c) and HCAs also found the subject hard to deal with. Whilst some HCAs

indicated that they would discuss the issue of prognosis, others tried to evade the subject unless forced to answer:

‘I... I try to, um... I try to get into another aspect of conversation, or... get their minds off that aspect. Sometimes you cannot help but um... you know, they want an answer. And I said “I personally don’t know, you’ll have to ask the doctor that”, you know?’ (*HCA M*)

Some HCAs reported patients wanting to tell them about issues relating to their lives. In the following extract the HCA reports about hearing a patient’s “confession” identifying her lack of familial ties as being an advantage:

‘Well, often it’s just about family, as well. Perhaps they’ve done something not very nice, and... You know, they just want to talk, I think. A lot of the time it’s just not...not for you to be answering you can tell that they just want to speak to you, really. Just somebody there that’s not really connected to them, and there’s nobody else there. So I think that a lot of the time, that’s... that’s it. I mean... They’re not, like I say, telling you secrets or things like that they just want somebody to talk to, ‘cause... I believe most of them know that’s sort of it... I think, well, I do believe most people know when they’re about to go’ (*HCA K*).

HCAs spend many hours with patients and if they visit the patient on several occasions they become quite well acquainted with the patient and their family spending time listening to the patient and answering their questions. As has been illustrated this can be a complex area and emotionally difficult for the HCA. Knowing how to deal with such questions was an important area for education identified by several HCAs. Some had done a communication skills training course organised by the local cancer network and had found this useful. Others were keen to do similar courses in the future:

‘Yes, this was last year.....they talked about it first of all and they did a role play of different situations in the house..... and then two ladies come on, that actually had had cancer themselves and that was wonderful because you realised how they felt and they told you how they felt when they first found out and all this and how it had gone on when they’d gone through the treatment, how the families had felt’ (*HCA N*).

‘And also, um... with people when you’re talking with people and how, if somebody wants to speak, it’s very easy to say, “oh, yeah, my uncle had that” and... you know, and... But that person wants to speak, so I think we need to have training things with how to speak, how to listen’ (*HCA A*).

6.8.3.4 Supporting the family

Most HCAs saw their role as supporting the family as well as the patient, offering to listen to them or act as a resource for them to pass on enquiries to others:

‘[I] introduce myself to the family, really just to give them the feeling of I’m there as a friend I’m there to support them, if they wanted to talk about anything that’s, you know, I’d be there to listen, any queries or questions I could put them onto the right people that would be able to help them and it definitely works, definitely works and in all the years that I’ve done Family Support it’s just the families are overwhelmed by our service, absolutely overwhelmed by it’ (*HCA F*).

HCAs recognised when relatives were shouldering a heavy burden in caring and would try to enable them to take a break from that role through encouraging the relative to leave the patient in their care for a while:

‘HCA: I’m actually worried about [partner] as well because I can see him physically not coping. He’s coped for a long, long time and now I know, I just know he’s not going to cope much longer.’

RF: ‘And what do you think or do or act in that situation?’

HCA: ‘Just try and talk to him, tell him to go out, he needs to go out, he needs to go away from the situation and not, and let us carry on because the more he’s around the more she’s erm, the more she gets anxious and she wants him all the time, you know there every second of the day. He needs to go away from her for a bit for his own sake, you know really and truthfully’ (*HCA D*).

Discussions with relatives about prognosis were also reported as being common and might intensify as death approached. An HCA might need to interpret what was happening for the relatives, who could be emotionally distraught, facing an unfamiliar situation:

‘Because I have found that, when somebody’s dying, the children come from far-away places, only to find that their parent is unconscious... and is quite comfortable, but they want to wake them up. And it’s hard to say, “please don’t do that”, you know? You have to say it because “if he wakes up, he’s not going to be the dad you knew”, which is very sad. In fact, you don’t say it in front of the patient I always take them outside, because you don’t know what a dying patient takes in, what they can hear. So you take them outside and try and calm them down and say, you know, “it’s better that your mum or your dad stays as they are”’ (HCA H).

In addition HCAs might need to contact the relatives when death is imminent or has recently occurred. This situation calls on their communication skills but also on their judgement as to when they should call, who they should call and what they should say:

‘I mean a man I was with he passed away and you get like a sixth sense and I thought his wife was riddled with arthritis upstairs and I thought, I don’t know why I didn’t, I thought “I’m not going to wake her I’m going to phone the son” and I did and he said “you haven’t told me mum yet have you” and I said “no”, and he said “oh thank God” and I thought “crikey”. For some reason I didn’t, usually you go and tell, you know, whoever’s upstairs, I thought “no I’m not going to tell her”, you just get this little bit of sixth sense and think “no I won’t tell her, I’ll tell the son first and then he can come” and they did and he was so grateful, you know, it was the best thing to do, I just thought because there’s no way she could have hobbled downstairs, nothing she could do, why upset her, you know so yeah’ (HCA E).

Many of these complex issues are familiar to those dealing with dying patients, however in a hospital or hospice, trained staff take these responsibilities. HCAs largely relied on intuition arising from experience having had little formal training in any of these aspects of their work, several referring to their skills as ‘common sense.’

HCF: ‘So how do you feel that you’ve gained the skills for the job?’

HCA: ‘Just by common sense and going to people, that’s er that’s the main thing, you know just, I mean every patient you go to is different and you just

where you do for one you wouldn't do for another, you know, it's all different experiences all the time (*HCA E*).

6.8.3.5 Costs of emotional labour

All HCAs spoke of the stress and emotional costs of the role particularly as they got close to patients and their families. Whilst all HCAs acknowledged the importance of continuity of care, a small group of HCAs described how they also needed a break from individual patients. One HCA expressed she needed to have breaks away from FSS working in the Fast Response Service, where deep relationships are not so readily built up:

‘I think yes.... you do need continuity.....But I mean a total break from palliative care, for me that's what I need, that's what I feel I need’ (*HCA D*).

Emotional support was received mainly informally from other HCAs or from family. A few HCAs knew nurses personally and received support from them. However, whilst HCAs could get clinical support from DNs on clinical issues, there was no mechanism for them getting support for themselves (Box 6-12), although some had grown close to individual DNs and would call them if needed.

Once you've done your three day training you are back and then back go into work. So the only, I mean we do get support when we're in work because I know I can phone the nurses and we've also got late call nurses through the night so we're not stuck with nobody if we need some support and, you know, obviously the doctors as well. You've got all that for your patient but you don't have much for self when you're working, it's quite mentally and physically as well, trying to support families and I feel that after a while you bottle up a lot and you just need to get it out of your system (*HCA F*).

Box 6-12 - Support from DNs

Conversely the costs of emotional labour seemed to be balanced by the rewards which emerged from caring. Many HCAs cited the gratitude of patients and their families as a reason for continuing in the role, despite not feeling valued by the PCT (Box 6-13).

Because I actually like the work and I believe in the service, I've always believed in the service I wish it was a bit more friendly, I wish things like that yes, but I don't stay because of my employers I stay because of the patients, that's me (*HCA D*).

I like it really..... I like the one to one with the patient. I like sitting with the patients, I like talking to them. I've met some wonderful, wonderful people (*HCA N*).

I get appreciated by the families, and it makes my job all worthwhile, when I know that I was able to put a smile on that person's face, that's all that mattered to me when I left there that I was able to support and help, and put a smile on their face before I left that's made my day, that's what works (*HCA F*).

Box 6-13 - Job satisfaction for HCAs

6.8.4 Enabling narrative reconstruction

In their emotion work with patients and carers, HCAs described how they provided support by being an active presence, performing caring tasks, listening and responding to their questions. This occurs in a social setting which spans the private and public, and professional and informal. This ambiguity, whilst problematic allows the HCA to occupy a space where they are close enough to be a confidante, someone who can hear even the most personal details as might a family member or close friend, but distant enough to not have the same personal or emotional involvement. The time they spend, relationships they build and emotional support they give enable them to assist patients and carers in a process of narrative reconstruction.

HCAs thus fulfil a role which professional carers do not easily fill because of professional distance and lack of time. In this section I will present a prolonged narrative of an HCA describing how she has supported an elderly mother whose daughter is dying (Box 6-14).

I've been to a really sad one this week her name is Claire (*not real name*).... She's just died and it was really sad because she died on her birthday, her 59th birthday. And her mum actually came in to visit her and the son came and he said "her mum's coming in to see her"....and she knew she was dying obviously, so when the mum come in she sat by her bed telling her how much she loved her... and I said "I'm just going a little walk down the garden".

So I left her on her own for a few minutes and then I came back in and I said "is it all right for me to come in" and she said "oh yes". And this lovely, lovely family, lovely, lovely lady and she says to me, she looked at me and she said "do you believe in fairies?" Well the funny thing is that week, a couple of weeks ago Richard and Judy was on the television, had been discussing people who believed in fairies and this lady actually saw fairies and she said if she saw the golden ones and believed in them, everything was going to be all right, but if you saw the silver ones they weren't. I just happened to see this programme and I said to this lady I said "well actually I do"....and she said about losing something. She said "I didn't want to come tonight but I want to be with her but I didn't want to come". I said "I know how you feel"...I said.... "I've got to say I felt a bit like it when my father died and I've never actually got over my father's death" so I said "you can't worry over things like that". She said "I know" she said "but I didn't want to come" she said "and I'm sitting here" she said "and I'm telling her how much I love her"..... and a mum saying goodbye to her daughter really wasn't it.....and I had to talk to her because she wanted me to talk to her.

And then she kept saying to me "do you believe in fairies?" and I said "well actually well actually" I said "yes I do" I said "I think they've helped me over times" and I said "I'm sure Claire has got two golden fairies sitting on her bed". And she said "do you know she said I'm really glad I've come tonight". "Now" she said "I feel a lot better". And we talked about these fairies and different things and I actually talked about my father and we talked about things and when it was time, the son came out to take her home and she put her arm around me and kissed me and hugged me and she said "I'm really glad I came to see her tonight" she said "I'm going to go home now feeling she's at peace"... (HCA N).

Box 6-14 - Do you believe in fairies?

In discussing this scenario I will use Layder's domains and concepts of emotion and power to explore the complexity of issues apparent within the narrative which illustrates how the HCA is able to assist the grieving mother. I have discussed *social settings* in Section 6.8.2 (page 263) in details, therefore in this section I will concentrate on the other three domains.

Situated Activity - Within this social setting the HCA must behave in a sensitive and supportive fashion. She feels that she needs to give space to the mother and dying daughter. Her presence is renegotiated at important junctures as the drama unfolds. Interaction between the mother and the HCA is both verbal and non verbal. The discussion is intimate with the HCA listening to the mother in her distress and sharing her own experience. The conversation then turns to fairies and the HCA continues to engage in the discussion seemingly aiming to support the mother in her distress. Whether she actually saw a golden fairy is unclear, however she successfully communicated that she could see one to the mother, enabling the mother to feel that her daughter was at peace and turning a distressing and perhaps fearful experience for the mother into a positive one where she is glad to have come. It seems that she has been enabled in some way by the HCA through a period of anticipatory grief.

Psychobiography. The HCA draws on her own psychobiography through this encounter. She 'knows' when to leave and 'knows' when to return, almost certainly informed by her experience over a number of years and her own skill at emotional management. Later in the interview when pressed to reveal how she has learned her job she explains how it is 'common sense'. She uses her own experience of her father's death and what she had heard about people believing in fairies to enable the support she gives. In her account this seems to be the crucial aspect of the encounter, since it allows her to connect in a deep way with the mother. It is not possible to gauge how significant this aspect is for the mother, although from the HCA's narrative it appears that it has helped her to make sense in some way of an extremely painful experience.

Contextual resources The activity in this setting is moulded by socio-cultural resources. The HCA leaving the patient and mother together and then returning illustrates a cultural norm of respecting privacy with loved ones in intimate moments

and personal solitude at times of distress. Conversely to leave the mother for a prolonged period would have been unacceptable and interpreted as being uncaring; but permission needed to be granted by the mother for the HCA to re-enter. Further contextual resources are drawn upon both explicitly and implicitly. The use of dialogue to offer support, the use of time and attention in the listening and the use of touch and a kiss to express thanks in an emotional context (which might have been out of place in other social settings). In caring settings such as this, many of these actions displayed both by the HCA and the mother are moulded by the ‘feeling rules’ (Hochschild, 2003) of this particular situation, which will govern the appropriate display of emotion.

Emotion This narrative illustrates how the HCA becomes emotionally involved quite naturally and unavoidably, she has in fact acknowledged this as she sets out to describe the narrative:

I have got involved because you can’t help get involved...(HCA N).

She describes the emotions and the reasons for them. In the text after this extract she explains how she deals with her feelings by buying flowers for her own mother.

Emotion effuses this scenario with words such as ‘sad’, ‘feeling’, ‘love’, ‘glad’, ‘hug’, ‘kiss’ and ‘emotional’ appearing throughout. Also emotion is implicit in the narrative as the HCA recounts the story of a mother attending her daughter’s dying scene. For instance, ‘saying goodbye’ is an activity accompanied by emotion and emotional displays – hugs, tears, promises not to forget each other etc. Ambivalence is also apparent in the mother wanting to be with her daughter but not wanting to attend that evening, a commonly reported emotion in those facing a loved one’s death (Worden, 1991). The construction of a close albeit brief emotional relationship between the mother and the HCA arises out of an empathic display of sharing experiences.¹⁸ The depth and emotional nature of the relationship is demonstrated by the embrace at the end of the contact.

Tears are not mentioned in this account although there is an indication from the tone of the HCA’s voice in the sound recording of the interview that recalling the scenario has the effect of inducing tears. There is no indication in this narrative of whether the

¹⁸ Some HCAs said that they avoided talking about personal experiences considering it professionally inappropriate; another example of the divide between professional and informal caring.

HCA needed to suppress tears at the time. Interestingly no HCA in this study describes actually crying in a patient's home.¹⁹

Power: Whilst emotion is striking in the narrative, issues of power are not so obvious, but no less important. A feeling of powerlessness is implicit in the account of the mother; the HCA reports how she empowered the mother, through negotiating her role, in terms of her presence in the room and responding to the mother's need to enter into dialogue. Once responding to the mother's wishes for company and conversation, reporting the discussion as being between equals as they settle into exchanging views and experiences of fairies.

Finally, the encounter seems to have empowered the mother for the future. She is no longer caught in powerless ambivalence, not knowing whether to be present or not with her daughter. She has completed an important task of sensing that her daughter is at peace and expresses her gratitude to the HCA in an embrace. This scenario exemplifies the claim by this and other HCAs that they are appreciated by patients and relatives and gain satisfaction from this. This is an important factor in 'empowering' HCAs to remain within their employment, despite a general feeling of being devalued by their employers.

6.9 Discussion

In any analytic process involving complex social phenomena the data will be incomplete and taken from certain perspectives. In this study we have access to HCA accounts about the caring situation in which they work and that of key informants. Caution is needed in drawing firm conclusions regarding the nature of their work and the extent to which they are involved in delivering care over and above the 'care work' for which they are employed. The examples which the HCAs chose to give may have been the most memorable for them and will not necessarily be typical of their routine work. However, the senior manager gives support to the concept of their extended role from her perspective in Box 6-8 (page 266).

¹⁹ Interestingly it is not unusual for Health Care Professionals to admit feelings of deep emotion with patient's at times – even tears; however for them there is the possibility of concluding an encounter as a method of coping with the emotion. For the HCA 'captive' in a patient's home this is not open to them. It might be that this precludes HCAs crying with patients and is an aspect which needs further exploration.

Assessing how effective HCAs are at supporting patients and carers should be explored from the 'users' perspective. Over 70% of carers assessed the Macmillan Carer's scheme as being very important to them in the care of their family member (Clark et al. 2000) and high levels of satisfaction have been reported with hospice at home services (McLaughlin et al. 2007; Exley and Tyrer, 2005). However, such schemes have different configurations and are provided in different contexts, so these findings do not necessarily apply to FSS. In addition few studies have explored in depth issues such as the role of HCAs in providing emotional support and enabling narrative reconstruction. This aspect needs further research.

Whilst only a fraction of the situated activity in any scenario is reported (the empirical is a subset of the actual), each person will also have a complex psychobiography which will not be fully accessible even with the most complete account of someone's life and psychological makeup. It is therefore only possible to be aware of a fraction of the effects of a person's psychobiography on any social situation. This does not negate the importance of psychobiography, but rather increases it, since it is vital in developing an understanding of a social situation to be fully aware of the possible contingencies brought by personal attributes even if these are only partially known. However certain psychobiographical aspects of HCAs emerged strongly in this study. HCAs seem to be mainly mature women, with a distinct vocational instinct, working conscientiously, reliant on innate skills and experience, achieving personal satisfaction through caring and offering emotional support. This suggests that they are the successors to members of the community described in the Queen's Nursing handbook by Wilmshurst (1943) as 'reliable women who will sit up at night with a patient and carry out orders intelligently' p28.

The social setting in which HCAs work is ambiguous involving both private and public space and a role that includes aspects of 'caring', 'carework' and 'professional caring'. The only reference to emotional work in the HCA job description is that they should work in a 'supportive and caring manner'. The extent to which HCAs develop their emotional labour is largely left to the individual, but it is constrained and enabled by strong social and cultural beliefs and expectations. A fairly consistent understanding of the extent of their caring role was described by all the HCAs interviewed, with the majority contrasting this with the failings of agency staff.

Whilst concerns over the work of agency staff also emerged in key informant interviews and are familiar to me from my clinical experience, the intensity of the feelings displayed by some HCAs may not be completely justified and could possibly contain an element of ‘scapegoating’ to remove the critical eye from their own work (Douglas, 1995).

Many HCAs continued working and caring despite having little formal psychological support provided by the PCT. All HCAs agreed that having an official support system which enabled them to discuss difficult issues and concerns arising from their work would be helpful. This positive response may have been enhanced by the HCF interviewing the HCAs, however, most of those interviewed had experience of the previous organisational arrangements where they did receive support and spoke about this very positively.

6.9.1 Conclusion

HCAs working with dying patients in the community undertake complex tasks, take levels of responsibility and possess skills which are not fully recognised. Similar reports from a variety of settings have been noted in the literature. This systemic blindness has risks for patients and their carers since the HCA’s work is not effectively supervised; it has high emotional costs for HCAs and exposes them to possible censure as they do their best to perform their duties. Understanding these issues is necessary to addressing them effectively. However, addressing these issues requires effective training and support systems to be established, an intervention which so far we have not been successful in developing. Whilst writing this chapter new opportunities to re-engage in this project have begun to emerge and it seems that now the HCF, who had in the interim undertaken important work with nursing home staff, may be able to recommence work with the HCAs and develop a support system with them. Thus the important task of enabling HCAs to move from ‘invisible’ to ‘visible’ emotional labourers is potentially going to recommence. Fortunately the HCF and the clinical/research team (apart from the research fellow whose contract has ended) remain in post and the insights gained from this study can be used to develop this programme. This illustrates the utility of a practitioner approach to research and development within a community of research practice an issue I will address in the final chapter.

Chapter 7 – Narratives and emergence: exploring complexity and practitioner research

7.1 Introduction

Narratives have featured prominently in the preceding chapters. Chapter-1 described the development of my own understanding of the complexity inherent in medical practice in primary and palliative care through professional practice within these disciplines. In Chapter-2 and Chapter-4 I presented a narrative of the development of primary and palliative care and palliative care research over the last 60 years. Finally in Chapter-5 and Chapter-6, I presented the results of research in which the narratives of palliative patients admitted as emergencies and health care assistants (HCAs) caring for palliative care patients in their homes are explored.

This chapter will explore in detail the function of narrative in exploring complex contexts within health care and its place in the expression of ‘tacit knowledge’ which defies precise propositional description. Narratives both contain and communicate complex messages and enable social development as individuals share stories and co-create them through their interaction. They may be collected and analysed in research in a variety of ways (see Box 5.0 page 267a). In this thesis I have used a critical realist approach to explore narratives illustrated by the narrative presented in Box 6.14 (page 278). Whilst Layder does not specifically utilise a narrative approach, I would suggest that using his domains present a useful method for analysing them.

To illustrate the function of narrative I will briefly explore their emergence as a tool within palliative care practice. I will then use the history of primary and palliative care and RCT research as presented in Chapter-2 and Chapter-4 to explore how narratives demonstrate the emergence of social structures (practice and discourse) over time and at varying rates. Arising from this I will challenge the use of Kuhn’s paradigms as a concept to define change within health related research.

In the middle section I will explore how narrative forms of knowing differ from propositional forms and their place in the maps and models we construct to understand and navigate through complex territory. Finally I will describe the emergence of what I have called the ‘community of research practice’ within the team in which I work, drawing on and developing Stacey’s concept of complex

responsive processes and linking this with Layder's theory of domains to produce a theoretical basis for a team approach to research and development in palliative care.

7.2 Narratives in palliative care

Narratives of care around the end of life are a fundamental aspect of professional care of the dying. Clark (1999b) comments that before the systematic studies of Cicely Saunders and John Hinton appeared in the late 1950s and early 1960s, medical writing on dying was confined mostly to 'idiosyncratic anecdote' p241 based on personal experience of caring for the dying and reflections on literary and historical work.

Much of Saunders' early work (1957 – 1967) takes a narrative approach as she recounts the clinical and personal histories of dying patients for whom she cared (Saunders, 2006). Her writing draws strongly on traditional Christian teaching in which preparation is made for the afterlife by those facing death, whilst also describing medical and nursing care offered to the dying.

The 1960s saw the rise of another dying narrative form, the 'atrocious story' p120 (Seale, 1998a), with examples including narratives from Sudnow's participant observation study describing care of the dying in two hospitals in USA (Sudnow, 1967) and Glaser and Strauss' seminal work on awareness contexts for the terminally ill (Glaser and Strauss, 1965). Seale suggests that this the atrocious story was given added impetus by the rise of the hospice movement and worldwide interest in 'stages of grief' theory (Kubler-Ross, 1969). Interestingly atrocious narratives seem absent from Saunders' early work, which takes a uniformly positive, if idealized approach. Atrocious narratives still continue to appear frequently in the medical press (e.g. Newton, 2007) often triggering a flurry of letters recounting similar stories from others. Another example of this form was the emotionally charged reactions from the public following the recent failure of Lord Joffe's 'Assisted Dying Bill' in May 2006.¹

¹ E.g. 'Any Answers?' Radio 4 13th May 2006.

Comparative stories of ‘good’ and ‘bad’ death attract a great deal of public interest, as demonstrated by Ester Rantzen’s documentary ‘How to have a good death’.² They have been used to challenge health care practitioners to consider the quality of their own practice – see Table 7-1.

<p>Mr B’s experience Reactive Patient Journey - Without GSF</p> <ul style="list-style-type: none"> • GP and DNs have ad hoc arrangements – no plan discussed or communicated • Problems with symptom control – high anxiety • Crisis call, e.g. out of hours – no management plan, handover form or drugs available • Admitted to hospital (bed blocks) • Dies in hospital – ‘over intervention/medicalised’ • Carer given minimal support in grief • No reflection/improvements by team/PCT • Inappropriate costly use of hospital bed 	<p>Mrs W’s experience Proactive Patient Journey - With GSF</p> <ul style="list-style-type: none"> • On SC Register – discussed at team meeting • DS1500 and info given to patient + carer (home pack) • Regular support, visits, phone calls – proactive • Assessment of symptoms – referral to specialist customized care to patient and carer needs • Carer assessed including psychosocial needs • Preferred place of care noted and organized • Handover form issued – drugs issued for home • Last days pathway/LCP, protocol used • Patient dies in preferred place – bereavement support • Staff reflect – SEA, audit gaps, learn, improve care <p><i>Key: SC Supportive Care; LCP Liverpool Care Pathway; SEA Significant event Analysis</i></p>
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Table 7-1 Comparative narrative from GSF flyer – 2005 (EoLCP, 2006)

Two problems emerge from these comparative narratives. Firstly, they assume a particular notion of ‘the good death’ characterised by an openly aware patient and carer as active participants in preparing for death and helped towards acceptance by expert psychological intervention (Walter, 1994), with the dying person as the ‘chief mourner’ p654 (Armstrong, 1987); the post-modern version of the heroic death (Seale, 1995). Secondly they frequently suggest that enabling patients to achieve a good death may be relatively easily achieved, for example by adopting a framework such as the GSF (Table 7-1). Joanne Lynn, a well respected physician and researcher into end of life care from the USA seems to support the notion of simple solutions when she wrote:

² Screened on BBC2 30th March 2006. One year on there is a BBC website linked to this programme and entitled ‘How to have a good death’, which enables people to upload home made videos where they discuss their ideas and proposals.

‘Without substantial cost and without substantial delay, every American could count on good care at the end of life, just as we now count on safe landings and waking up from anaesthesia. With good care, most of us, lucky or not, could live comfortably and meaningfully, right up to the end’ p2 (Lynn, 2000).

1. GOOD MEDICAL TREATMENT: You will have the best of medical treatment, aiming to prevent exacerbation, improve function and survival, and ensure comfort.
2. NEVER OVERWHELMED BY SYMPTOMS: You will never have to endure overwhelming pain, shortness of breath, or other symptoms.
3. CONTINUITY, COORDINATION, AND COMPREHENSIVENESS: Your care will be continuous, comprehensive, and coordinated.
4. WELL-PREPARED, NO SURPRISES: You and your family will be prepared for everything that is likely to happen in the course of your illness.
5. CUSTOMIZED CARE, REFLECTING YOUR PREFERENCES: Your wishes will be sought and respected, and followed whenever possible.
6. USE OF PATIENT AND FAMILY RESOURCES: We will help you consider your personal and financial resources and will respect your choices about using those resources.
7. MAKE THE BEST OF EVERY DAY: We will do all we can to see that you and your family have the opportunity to make the best of every day.

Source:(Lynn, 2000) p3

Box 7-1 - "Promises that seem to make a difference"

Furthermore Lynn suggests ‘promises’ can be made to the patient in place of being able to offer a cure (Box 7-1).³ Likening achieving a good death to landing an aircraft or waking from anaesthesia arguably adopts an inappropriate metaphor, since both represent relatively simple linear systems in which there is a high degree of predictability, albeit requiring skilled technicians to achieve safe results. In reality the dying face highly complex and frequently chaotic situations (Frank, 2004) as illustrated by the data presented in Chapters 5 and 6. Therefore whilst striving to achieve these aims is a professional and ethical imperative, promising these as outcomes would seem highly risky.⁴ Developing a robust service to provide effective palliative care in the community needs attention to the complexities of the context in

³ These promises are interestingly reminiscent of the ‘Patient Charter’ introduced by the Major government in the 1990s.

⁴ I make this judgement from clinical experience as well as evidence from this thesis which indicates the complex nature of community palliative care.

which it is delivered. Considering narratives at many different levels from the patient to society as a whole can assist in this process. This will be considered in the next section.

7.3 Narratives in time

By their very nature narratives flow through time producing histories with a beginning, middle and end (Polkinghorne, 1988). However, narrative histories are not just ‘one damned thing after another’⁵ they illustrate specific perspectives and assign meaning to events. Somers (1994) asserts that social life can only be understood through narrative, whilst Abbott (2001) taking a realist approach suggests even more assuredly that:

‘Narrative organisation [is] real; that is, it [is] inherent in the social process itself and not merely our talking about that process’ p289.

The concept of the emergence of social structures over time through social interactions is fundamental to both the theory of domains (Layder, 1997) and complexity theory (Byrne, 1998). Emergence occurs at varying rates, so different timescales need to be considered to observe the emergence of social structure at different levels. In general the ‘time horizon’ for the emergence of micro structures, e.g. personal relationships is much shorter than for macro-structures, e.g. political systems (Abbott, 2001). Examining narrative histories enables us to demonstrate this emergence although it is important to avoid a ‘Procrustean’ error in which the narrative selected is made to fit the theoretical construct. Bearing this in mind I will describe the timescales of emergence apparent in the data presented in this thesis.

7.3.1 Narratives of patients and others

As discussed in Chapter-5 (Section 5.1.2 page 167), patients becoming chronically unwell need to adopt a new narrative (narrative reconstruction) in order to make sense of the losses they face and the threats to their sense of ontological security (Mellor, 1993). Patients with advanced disease often face a rapidly changing condition and therefore need to adjust their narrative continuously. Thus, the narrative surrounding emergency admission to hospital may become incorporated

⁵ This saying is attributed to various people including Winston Churchill who apparently used it to explain why predicting the future on the basis of the past was futile.

into their illness narrative depending on the significance it holds for the patient. Thus for the patient, narratives will have periodicity ranging from a short time (hours or days) to their whole lifetime. These narratives will all be implicated in each other in a complex interacting biography. Saunders was aware of this in her work suggesting that that ‘the whole experience of [a patient’s] life [is] reflected in a patient’s dying’ p1601 (Saunders, 1996).

Whilst individual life narratives are emergent through a complex interaction of experience and meaning, illness narratives may also have agency in affecting social change. For instance patient and carer narratives might influence the development of hospices and palliative care locally and nationally through being publicized in the media.

7.3.2 Emergent social structures

The emergence of organisations and social structures is most simply recounted in narrative form.⁶ The time horizon of organisational emergence will vary greatly, with some organisations evolving very slowly, e.g. the Westminster Parliament, whilst others having a very short cycle, e.g. the rise and fall of ‘dotcom companies’ or the NHS University (NHSU), disbanded after 18 months despite a high profile launch which included ministerial predictions that it would ‘change the culture of the NHS’ (NHSU, 2004).

In Chapter-6 (Section 6.4.1 page 248) I described briefly the history of the action research project exploring the work and support needs of HCAs by members of the community palliative care team. This team has evolved as it has responded to national strategy, local needs and funding opportunities, but also through the interactions of team members through which a team narrative has emerged. This will be considered in more detail in Section 7.6 (page 301) when I consider its development in terms of a community of research practice.

Organisations normally have fairly well defined boundaries, although these are porous allowing them to be influenced by governmental, personal and social factors. Other social structures - forms, practices and discourses – are amorphous but they

⁶ Most organisational websites have a section devoted to the history of the organisation to explain its current structure and function.

also display varying cycles of emergence which may be apparent in historical narratives.

In Chapter-2 and Chapter-4 I describe the history of the development of community palliative and primary care and the development of research practice as they have emerged over the 60 years since the inception of the NHS. In terms of clinical practice I have defined three distinct time frames or time cycles of 20 years, whilst research I have explored as one longer timeframe. Whilst these cycles are analytical devices, I would argue that they do illustrate real cycles based on the empirical data emerging from the literature. No doubt there are other cycles contained within and encompassing the ones I have defined. Similar cycles might be seen in the emergence of narrative forms in palliative care as described in Section 7.2.

7.3.3 The centring and decentring of ‘biographical medicine’

The first cycle, 1948 – 1967, for both palliative and primary care demonstrates the emergence of biographical medicine (Armstrong, 1979; Seale, 1998). Biographical medicine is characterised by a *professionalized* bio-psychosocial approach based on psychodynamic theory and psychotherapeutic practices (Seale, 1998) which over this period as Armstrong suggests had the effect of decentring ‘Hospital Medicine’. The dominance of Hospital Medicine itself had emerged through the rise in medical science in the first decades of the 20th-century during which time the role of the GP had become subordinate to specialists. Hospital Medicine became the producer of knowledge, whilst general practice provided the patients through referral to the hospital specialist. Biographical medicine provided a new ‘specialist role’ for the GP based on modern scientific medicine and a psychosocial approach; thus:

‘Biographical medicine did not deny traditional organic pathology but relegated it - and its enveloping cosmology of Hospital Medicine - to a subsidiary part of the GPs’ task’ p5 (Armstrong, 1979).

As described in Chapter-2 general practice in the 1950s and 1960s emerged to occupy this space principally through the work of Michael Balint (Balint, 1957; Marinker, 1998).

Care of the dying as developed by Saunders culminating in the mid-1960s also became characterised by biographical medicine (Seale, 1998). However, unlike

general practice where clinical practice had become increasingly based on the scientific model of hospital medicine, the practice of terminal care emerged from the earlier 'pre-scientific' tradition of 'bedside medicine' which was characterised by the centrality of the patient and their concerns and the doctor's response to them, mainly a privilege of the rich (Armstrong, 1979). Bedside medicine is evident in the writing of the 1930s and 1940s as an approach to the care of the dying (Leak, 1948; Worcester, 1935; Horder, 1948), a subject concerning which Hospital Medicine is largely silent (Clark, 1999). Thus, the evolution of terminal care from 1948 to 1967 involved not only a movement from 'bedside' into 'biographical' medicine, but the development of a scientific basis for care of the dying also.

The second period, 1968 – 1987, saw professionally led developments within both general practice and palliative care. 'The consultation', the central tool for the delivery of biographical medicine for the GP (Bosanquet and Salisbury, 1998) was greatly developed at this time (Neighbour, 1987; Pendleton et al. 1984; Stott and Davis, 1979; Byrne and Long, 1976), becoming the major focus of vocational training for GPs. As discussed in Section 2.4 (page 57), palliative care was in its formative phase with remarkable expansion in hospice numbers, 'exporting' its version of biographical medicine with the rapid rise of community and hospital palliative care teams and the establishment of palliative medicine as a medical specialty in 1987 (Hillier, 1988).

1988 – 2007, the third period, saw general practice and palliative care maintaining their ideals within biographical medicine, but becoming constrained by a more bureaucratic approach to healthcare. General practice increasingly worked within a framework of clinical and efficiency targets first introduced in the 1990 contract (Bosanquet and Salisbury, 1998). Palliative care being brought increasingly into the mainstream of healthcare provision underwent a process of routinization from its independent and charismatic roots (James and Field, 1992); it also embarked on a quest to define its evidence base (Section 4.2.8 page 139) culminating in the publication of the NICE guidelines for supportive and palliative care in cancer in 2004 (NICE, 2004). In this period central government took on an increasing role, not just in defining direction of policy but in directing professional practice itself, with

Fordist principles of standardization and regulation being applied increasingly to clinical work (Harrison and Ahmad, 2000).

In 2007 there are signs that primary care and palliative care are in the early stages of a new cycle. These are most clearly illustrated by the new GP contract for primary care and the emergent entity 'End of Life Care' as a possible successor to palliative care.

The 2003/4 GP contract removed primary responsibility for the care of individual patients from the GP to the practice; has resulted in most practices 'opting out' of taking 24 hour responsibility for their registered patients; and has increased the GP's role in primary and secondary disease prevention, with a substantial proportion of GP pay being dependant on achieving targets in this area (BMA, 2003). This has implications for the traditional GP role of providing personal continuity of care (Freeman et al. 2003) and has raised concerns that attention in primary care is moving away from the 'old, poor and sick to the young, rich and well' p320 (Heath, 2004). Whilst this new approach is reported to have achieved positive results for chronic disease management in areas such as diabetes (Kenny, 2005), concern remains regarding its effects on delivery of palliative care by GPs (Walton, 2005).

The emerging changes in palliative care are not as clearly defined, being at an earlier stage of evolution but are arguably no less real. Until recently 'end of life care' was a term used predominantly in the USA, originally arising out of concerns regarding patient choice at the end of life in the context of increasing technological health interventions in the late 1970s to 1990s (Soloman, 2003). In Britain patient choice over place of death had been an important issue on the professional agenda for a number of years (e.g. Thorpe, 1993) however it has emerged as a central aspect of the government's vision for choice in the NHS, which was laid out in a White Paper in 2003 (DH, 2003). This was closely followed by an announcement by the Secretary of State for Health of a £12 million grant over three years (i.e. £4 million per year)⁷ designed to enable choice over place of death to be realised. Although this was a very small sum it enabled the 'End of Life Care Programme' to be established in July

⁷ This announcement was apparently made without the knowledge of DH civil servants (personal communication Peter Tebbitt).

2004 (NHS, 2004), which became the main focus for Department of Health strategy for palliative care.

In January 2006 the White Paper on community care (DH, 2006a) built substantially on the concept of end of life care, proposing that 'end of life care networks' were established. Finally, in July 2006 the Minister of State for Health announced the development of a 'national end of life care strategy' (DH, 2006b), which she proposed 'will affect how we care for dying people for years to come'.

Unlike the professionally led early developments in palliative care, issues around end of life care have been centrally driven by the New Labour government through the Department of Health led by the National Cancer Director⁸ with national charities, local organisations and health care professionals cast into a responsive rather than a leading role. The National Council for Palliative Care has warned that the definition of end of life care is unclear and needs to be addressed as a matter of urgency (NCPC, 2006). Nevertheless end of life care is undergoing a process of reification, being described as a 'specialty' needing an 'evidence base' p521 (Kendall et al. 2007) and a journal 'End of Life Care' being recently established (Hansford et al. 2007).

Despite being centrally driven, the overall end of life care policy has emerged piecemeal. The end of life networks announced in the 2006 White Paper have not been developed so far, however, the end of life strategy which was not featured in the White Paper has now become the central focus. How this strategy along with other radical changes in the NHS will affect the future development of palliative care remains to be seen, however I would suggest that the evidence I have presented in this thesis supports the notion that for any national strategy to be successful it should allow services to develop in a fashion appropriate to the particular local context.

7.3.4 Narratives in the development of medical research

Chapter-4 explores the parallel development of medical research, in particular the RCT and palliative care research. The RCT has developed over 60 years, with the first modern randomized trial being reported in 1948. This research has continued to grow since that time, steadily in the first 25 years and accelerating following

⁸ National Clinical Directors are appointed by the Prime Minister's office to work in the DH.

Cochrane's challenge in 1971 to establish a programme of RCTs and systematic review for all areas of clinical practice and again in the 1990s following the advent of EBM - the popular outworking of Cochrane's vision.

Eisenberg (2001) asserts that RCT evidence within the context of EBM represent a Kuhnian paradigm shift within medicine. Is this a justifiable claim? Kuhn suggested that within a particular paradigm, science progresses as 'normal' with scientists using methods and concepts to research questions arising from within the limited vision of the paradigm (Kuhn, [1962] 1996). A scientific revolution occurs when one scientist or a group propose a new set of ideas to explain new data or as a method of overcoming past inconsistencies. Inevitably this new paradigm presents a challenge and threat since it necessitates a change in 'world view' and is thus resisted by the main body of scientists who continue performing 'science as normal' until the new paradigm becomes accepted. A good example of this is Einstein's general theory of relativity which although proposed in 1916 was not widely accepted until 1919 when it was tested empirically during a total eclipse of the sun. All of Kuhn's examples are from astronomy, physics or chemistry with no examples arising from any other area of science, posing a question of whether his thesis holds within biological and applied sciences (Fuller, 2003).

If we do accept Kuhn's proposal as broadly applicable, was the rise of the RCT such a revolution? Certainly Doll and d'Arcy Hart describe the sudden emergence of the modern RCT in 1948; however whilst this was resisted in some quarters, concern arose mainly regarding the ethics of randomisation rather than serious scientific objection to the method (Doll, 1998; Hart, 1999). In addition, RCTs were not unknown before that time and had been used in agriculture for many years. What seems more likely to account for the rise of the RCT is a process of emergence aided by certain 'tipping points' namely: the need to test a plethora of new treatments resulting from the rise of clinical science; the impressive results from the streptomycin trial; the personal commitment and persuasive powers of Bradford Hill and others; and the availability of funds for research and the 'ready availability' of patients for recruitment in the new NHS (see Chapter-4).

Drawing on Fuller (2003) I would suggest that Kuhnian revolutions are unlikely to occur in applied clinical research because of the lack of *absolute* precision. In the

physical sciences exploring deterministic laws, if experimental data does not fit, there must either be a problem with the data (which can be subjected to further experiment) or new theoretical explanations must be found. Main stream health service research functions with *probabilities* where there is a lack of precision and it is unlikely that a new paradigm would emerge because of a poor fit of data. A change in research paradigm is only likely to emerge through challenging the philosophical assumptions of health services research, as I have proposed in Chapter-4. Thus I agree with Corner (1996) that palliative care should define its own research paradigm rather than 'leaving it to the chance that a Kuhnian revolution might occur' p207 (ibid), since the odds for this happening are extremely long.

Observational research taking a positivist approach was espoused by Claude Bernard in the middle of the 19th-century (Bursztajn et al. 2000). Since RCTs are fundamentally a refined form of observational research (Sehon and Stanley, 2003) in the same positivist tradition, the history of medical research up until the present day forms a particularly smooth continuum from the time of Claude Bernard.⁹

In fact the modern scientific approach can be traced to the mid 17th-century - to the philosophy of Descartes and the rise of analytic philosophy. His work has defined the course of modern scientific method from that time until the present, characterised by a reductionist approach in which a decontextualized universal and abstract understanding is sought. Thus physics, the science most amenable to abstract mathematical description, is considered the purest science (Toulmin, 1990).

In the 20th-century the privileged position of science and analytic philosophy have come under increasing pressure through a crisis in confidence in science particularly because of science's technological products – most notably the nuclear bomb – and its environmental effects; and the philosophical work of Wittgenstein (1889-1951) who challenged the notion that there is a direct link between language and objects themselves. Toulmin (1990) argues that the emergent interest in a narrative approach to knowledge represents a rediscovery of a holistic philosophy developed by the Renaissance humanists which was marginalised in the mid 17th-century in favour of the reductionist Cartesian approach.

⁹ Arguably Claude Bernard would have understood RCT evidence following a tutorial on modern statistical methods.

‘What has to be yet explained is why these two traditions were not seen from the beginning as complementary, rather than in competition. Whatever was gained by Galileo, Descartes and Newton’s excursions into natural philosophy, something was also lost through the abandonment of Erasmus and Rabelais, Shakespeare and Montaigne’ p43 (Toulmin, 1990).

7.3.5 Emergent social structures – conclusion

Thus taking a narrative approach enables the varying timescales in the emergence of social histories to be examined, illustrating different cycles in the development of primary care, palliative care, medical research and their relation to the history of modern thought – with cycles having a time horizon varying from a few years to four centuries. This approach also enables an exploration of the generative and contingent factors involved in these cycles including the agency of individuals (such as Saunders, Bradford Hill and Cochrane), professional practices, government policies and the overarching effect of dominant discourses. This facilitates a deeper understanding of the historical and social roots of current health care practice and allows a critical position to be taken as a balance to the hegemony inherent in current modes of thought.

7.4 Forms of knowledge beyond the propositional

There are different ways of presenting and communicating information, concepts, theories and truths. The preferred method in science since Descartes has been the proposition; statements which are either true or false and can be verified as such. Science and technology based on the precise elucidation of generalisable rules expressed in propositional statements (mathematical formulae are the ultimate propositional statements) has been phenomenally successful in developing the modern world and medicine has been no exception to this.

In medicine and health care what counts as formal evidence normally takes a propositional form. Evidence based health care advises us on the probability of a particular intervention being effective in a particular context. Guidelines built on the findings of EBM advise us what to do in certain situations, often giving us a range of actions to take according to the specific circumstances and sometimes providing us with an algorithm to enable *the* correct decision to be made.

In complex clinical contexts the situation is often imprecise and messy, where propositional statements may not offer an adequate description (Hunter, 1996). Cognition here relies to a large extent on ‘tacit knowledge’ (Pancaldi, 2003),¹⁰ and intuition (Barraclough, 2006), where making the correct decision may even depend on a degree of luck (Weingarten, 2003). Whilst guidelines might be generally desirable to ensure treatment is standardised, even for ‘simple’ conditions such as hypertension they may be only applicable to a fraction of patients with the condition because of the prevalence of concurrent illnesses (Hart, 1993; Fortin et al. 2007). Despite advances in clinical science, complex clinical situations will never be reducible to simple ones (Fulford et al. 2002) and therefore methods other than algorithmic guidelines will always be necessary (Lipman, 2004).

Schon (1991) develops this theme arguing that knowledge beyond the scientific and technical is fundamental to the skill of a practitioner. He suggested that professional practice involves two distinct forms of knowing: ‘technical rationality’ - knowledge which can be precisely described and ‘reflection-in-action’ - knowledge which emerges through practice which encapsulates both tacit knowledge and professional judgement.

Tacit knowledge, intuition and reflection in action are all concepts which in themselves defy propositional description but are none-the-less real and essential ingredients of life and professional practice. It seems that these rely on another form of knowing which Polkinghorne (1988) has identified as– ‘schematic knowledge’. This takes two forms ‘spatial’, as in pattern recognition¹¹ and temporal ‘narrative knowing’ p111 (ibid). Whilst narratives contain propositional statements, the meaning conveyed by narrative is in excess of the propositional statements contained within it. Thus:

‘The sentences “Her husband was very ill”, “He died”, and “She is sad and lonely”, produce a discourse of narrative meaning that is greater than the sentences alone’ p32 (ibid).

¹⁰ Tacit knowledge was coined in 1950 by Michael Polanyi, chemist and philosopher of science as a challenge to the concept that science should rely on propositional knowledge alone. One example he gave of tacit knowledge was being able to recognise a face without being able to explain how.

¹¹ Pattern recognition is an important form of knowledge in action. A chess grand master and a radiologist have well developed skills in pattern recognition (Wood, 1999).

Propositional and schematic forms of knowledge are necessary for models and maps which are developed to understand and ‘navigate through’ complex territory (Stewart, 2001).

7.5 Narratives as maps

In Chapter-4 when I discussed a critical realist approach to research in palliative care, I highlighted the important distinction between the ontological and epistemological realms in science. Critical realists argue for the existence of external reality, however our experience of the world is mediated through our senses and our understanding of it is based on previous experience and abstract concepts, making our knowledge both partial and fallible. In order to understand the real world (territory) and to navigate through it, we maintain a representation (map) of the world in our minds. However, our maps and models are only representations of reality - as philosopher Alfred Korzybski (1879-1950) pointed out – ‘the map is not the territory.’ A map cannot represent the whole territory; it will be partial and will reflect the perspective, purpose and world view of the map maker.

Practitioners develop conceptual models or maps to understand complex clinical contexts (Misselbrook, 2001; Heath and Sweeney, 2005) which will vary according to the specific task. Biomedical maps are central to modern medical practice and are used by generalists and specialists alike, e.g. central crushing chest pain is likely to indicate serious cardiac ischaemia; the patient needs urgent attention (Heath and Sweeney, 2005). These maps may be transformed into guidelines which might be categorised as formal maps describing territory in a highly idealised and propositional form. Guidelines may be useful for decision making in relatively simple and linear contexts; however, a practitioner of biographical medicine will need to simultaneously use psychosocial and cultural maps in addition to biomedical ones to function effectively (Misselbrook, 2001).

Narrative provides a useful cartographic tool for constructing maps to guide health care professionals through complex, highly individualized terrains (Greenhalgh, 1999),¹² and is the central way in which clinical knowledge is learned and brought to mind at the appropriate time (Greenhalgh and Hurwitz, 1999). Whilst narratives alert

¹² Greenhalgh seems to conflate all non propositional forms of knowing as ‘narrative’, which I think is a mistake since spatial knowledge is important yet distinct from narrative.

the clinician to standard memorised scripts (such as crushing chest pain) they may activate minimal cues based on experience over years. For instance, Greenhalgh (1999) describes a situation in which a GP leaves his busy morning surgery to visit a child with diarrhoea who was ‘acting strangely’ to find that she had meningococcal septicaemia. On reflection the trigger to visiting seems to have been the unusual use of the term ‘acting strangely’ which did not fit with the usual illness scripts associated with children with viral diarrhoea, or the GP’s previous experience of this family.¹³

Maps of complex health territory as used by practitioners develop iteratively mirroring the changing context, unlike geographical maps where the territory is *relatively* fixed. Schon likens this complex type of territory to a ‘swamp’ (Schon, 1991). In the swamp there may be familiar objects which can be named and described in propositional terms, however their relationship to one another will shift in the fluid terrain. There might even be rock outcrops which are enduring landmarks which help to locate and make sense of the other more changeable aspects. Applying this metaphor to professional practice, it is on the rocky places of relative certainty where technical rationality can most easily be applied (e.g. ‘this sounds like a chest infection, it will hopefully respond to antibiotics’) whereas the knowledge based on experience and intuition is called upon to navigate the swamp (e.g. ‘it seems that the pain being described here may have a large emotional element attached to it’). As uncertainty increases, propositional forms of logic become less useful and intuitive logic becomes central to map construction.

Over time the skilled and experienced practitioner (or indeed the expert patient) will have built up a map of the territory in which they operate— or in fact a series of maps largely based on narratives, which are available and can be called upon for different situations. Selecting the map with the ‘best fit’ for the situation described is part of the ‘reflection-in-action’ of the experienced practitioner. In dealing with a specific ‘case,’ as information becomes available various maps are accessed and aspects from these are selected and incorporated into a new map whilst other bits are discarded. It is not so much that a jigsaw is built up as more pieces become available, but the

¹³ Greenhalgh estimates that GPs see meningococcal septicaemia on average once in every 96,000 consultations.

picture itself actually changes and some jigsaw pieces which were incorporated before are discarded as no longer being helpful.

7.5.1 Constructing and using multilayered maps

Historical narratives are maps created which link relevant events into a temporal framework. When a patient gives a narrative account of the process which led them into hospital (Chapter-5), they will describe certain aspects of the process and leave out aspects which they consider irrelevant. Their narrative will include the protagonists, events and causal sequences they feel are important or relevant to the purpose of the narrative. Furthermore, the construction will be influenced by the interviewer's presence through non verbal means, such as eye contact, nods, smiles, frowns, looks of disbelief etc as well as through direct questioning. Thus the narrative is not just the patient's construction, it is co-created in the space between the narrator and the listener (Robinson, 2004). In addition if the interviewer is going to write up the narrative (as I did in the study in Chapter-5), aspects of the patient's story are combined with the interviewer's own map, to provide the third person account. However much the interviewer might try to 'bracket' their previous understanding and assumptions, it is not possible to do so completely and therefore the recorded narrative will be a further co-construction and must be read in that light.

Continuing with the example of Chapter-5; by exploring various narratives and comparing and contrasting them it was possible to build up a picture of the common issues related to hospital admission. Various maps could be constructed based on these narratives. Figure 5.4 (page 199) is a literal 'cartographic' map, illustrating the routes taken into hospital; whilst analysing the problems patients faced and the reasons behind the action they took which led to admission enabled a series of other maps to be constructed. DNs themselves constructed maps of strategies available to them to access GPs on behalf of their patients.

Thus, narrative based research enables detailed maps to be constructed from many different perspectives concentrating on different aspects to produce a depth of understanding of a complex social situation, in a fashion similar to a collection of maps needed to gain a deeper understanding of a city (e.g. road map, underground map, geological map, electoral map, etc).

Incorporating depth realist constructs into maps emerging from narrative research allows ontological depth to be added to them. For instance, exploring the territory of HCAs working in community palliative care using Layder's domains and the theory of emotional labour (Chapter-6) enabled a multilayered conceptual map of their work to be constructed, where issues of emotion and power related to their work and the social setting which they occupy could be illustrated. Including such ontological depth enables a richer understanding to emerge than if the map was constructed following an empiricist approach considering only the interaction order.

7.6 Developing a community of research practice

In this section I will explore the development of the community palliative care team into a 'community of research practice' which has occurred over four years. Part of its history was described in Section 6.4.1 (page 248) but it will be expanded further in this concluding section of the thesis in which I argue for the value of this approach to developing an evidence base in palliative care.

Communities of practice are a method of learning, problem solving or research in which practitioners function beyond their normal contracted roles (Wenger et al. 2002; Friedman, 2001). They are defined as:

Groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis p4 (Wenger et al. 2002).

They encourage creativity and professional development and have the potential to enhance the core functioning of the team as the 'learning' from the community of practice is fed back into the team (Wenger et al. 2002). Honeyman (2002) suggests that because of the complex nature of their practice, communities of practice are particularly appropriate to primary care teams since the skills involved in providing health care in this context and the skills needed to function effectively in a community of practice are complementary. This I believe applies equally to palliative care teams.

The core function of the community palliative care team of which I am a part is to work in partnership with primary care teams providing specialist palliative care services in the community and also to offer educational support. Macmillan nurses,

the main professional group in the team, work with DNs and GPs to form ‘supportive triangles’ for palliative care patients. They also co-ordinate patient care with other professionals within the team: palliative medicine specialists, the physiotherapist and occupational therapist; and with the wider health and social care community: hospice, hospital team, oncology staff, social workers etc. Whilst the functions of the team can be defined in job descriptions, contracts of employment and operational policies, this can only be achieved in outline since the complexity involved in the day to day work is high and defies precise description.

As with any social grouping, the team has evolved over time with its relationships and practices emerging through interaction (*situated activity*) between team members working within the *social setting* of a health care multidisciplinary team in the early 21st-century. This emergence is enabled and constrained by various *contextual resources* of professional ethics, NHS operational policies, palliative care philosophical principles etc. The *psychobiographical* attributes of each team member are also important factors in influencing team evolution, with some members being particularly skilled in teaching, others in mentoring, leadership etc.

In their study of 44 Macmillan palliative care teams Clark et al. (2002) noted a high degree of variability in how teams functioned, resulting from differences in team composition and working conditions. They conclude that for teams to be successful in addition to adequate support,¹⁴ they require a high degree of reflexivity to develop good working relationships. They noted how service variability was in tension with the modernist idea of an organisation as a machine, the preferred metaphor within the NHS, by which practices and outcomes need to be predictable and standardized.

Interestingly, Ralph Stacey, drawing on complexity theory, argues that variability within organisations (which he terms ‘deviance’), is vital for organisational creativity and development (Stacey, 2006). Therefore, rather than this variation representing a problem it could be seen as a vital ingredient in teams. I will examine this further in the next section when I explore a theoretical basis for team working in general and a community of practice in particular. For this I will draw on the work of Stacey, which I believe offers a useful additional insight to Layder’s domain theory.

¹⁴ Accommodation, computers, telephones etc.

7.6.1 Theoretical basis of a community of practice

Stacey takes a fairly radical view of the nature of organisations (Stacey, 2001; Stacey, 2006). He rejects the notion that outcomes within an organisation can be engineered, either in terms of the traditional ‘scientific management’ practice of command and control, based on the assumption of linear processes and rational decision making (i.e. the dominant NHS concept) or the more ecological concept of the ‘learning organisation’ (Senge, 1990) whereby levers for change are identified by managers who can work on these to steer the organisation towards a ‘global pattern which has been identified before hand’ p138 (Stacey, 2006). Basing his theoretical approach on the symbolic interactionism of G.H. Mead and drawing on complexity theory he suggests organisational emergence can be seen as resulting from ‘complex responsive processes’ by which global structures in organisations emerge entirely from interactions between individuals.¹⁵ Global engineering, either by command or control or by leverage is never possible since emergence within a complex system is unpredictable resulting from non-linear dynamics.

‘Central to the complex responsive process perspective is the notion of emergence, according to which global patterns continually emerge in local interaction, and this means that they come about in the absence of global plans or designs, or if there are such global plans and designs, they will not be operating as the cause of the global pattern that appears, because that global pattern is emergent. So, in these circumstances, any strategic planning, organizational leverage activities are largely fantasies whose function might largely be to form social defences against anxiety’ p139 (Stacey, 2006).

As with other complexity theorists (and in keeping with his own earlier diagram Figure 1-1.page 32) he does espouse the concept of organisations operating within the zone of complexity. This he identifies as the area where innovation and change emerges.

‘If there is little misunderstanding between people forming a group with well established concepts and ways of talking to each other, their conversations are

¹⁵ Stacey rejects identifying organisations as systems, since in his view this would preclude human agency. He has therefore coined the expression ‘complex adaptive processes’ to describe how interactions between individuals display similar characteristics to computer simulated complex systems in which (paradoxically) interacting elements have no agency.

likely to be repetitive. If there is too much misunderstanding between people drawn from very many disparate groups, then there is the disintegration of communication, "a tower of Babel". This is where the tension between conformity and deviance becomes important. It is this deviance that imparts the internal capacity to spontaneously evolve new patterns of conversation, that is, new conversational attractors. The conditions for creative, fluid conversations lie in some critical range between these extremes' p143-144 (Stacey, 2001).

This I believe provides a powerful insight into how organisations develop and adapt. Rigid organisations where rules and protocol are followed and deviance is not permissible fossilize and cannot adapt effectively to change; whilst chaotic organisations will disintegrate as there is no common language. This adds an additional explanatory concept to Layder's domain of situated activity where social structures evolve through social interaction. In organisations such as the NHS which are trying to control development, to achieve strategic aims and to maximize efficiency, the belief is that deviance must be eradicated as this indicates lack of control and waste. However, adopting this approach stifles creativity and frustrates rather than enhances organisational development. Some organisations require a command and control structure, such as a military unit, or arguably an operating theatre where processes are more linear and predictable.

A problem with Stacey's approach is that he offers no explanation as to why conditions for communication exist within an organisation at all. Why do they not dissipate through lack of coherence? I propose that to achieve the conditions for meaningful interaction it is necessary to acknowledge the constraining and enabling influence of social settings and their available contextual resources. In addition whilst Stacey recognises the reflexive nature of individuals, who can modify their interaction with others, he fails to acknowledge the important contribution of psychobiography to this reflexive interaction.

I also think that Stacey rejects Senge's 'learning organisation' (Senge, 1990) too readily. I would agree this might represent an idealized vision of organisational change which could fail to take into account the unpredictability of emergence resulting from non-linear dynamics. However the constraining and enabling effect of social structures, which will include professional practices; cultural and social norms;

the ability of practitioners to learn from experience; to reflect and control their interactions and to work towards achieving desired ends does influence organisational emergence and allows a degree of control. However surprise occurrences and paradox will also be apparent and problems will arise not only through systematic failure, but as chance events within a complex system.

My proposal is that a synthesis of Layder's realist approach (with its attention to ontological depth) and Stacey's complex adaptive process (providing insights into the mechanisms of interaction and emergence) provide a coherent approach to understanding organisations such as the community palliative care team. Viewing the team in this way gives a theoretical basis to the concept of the palliative care team as a 'community of practice'; a categorisation which presents a more neutral position with regard to the likely emergence than is implicit in the term 'learning organisation'.

7.6.2 The emergence of a community of research practice

In considering the development of my own team it is apparent that the process of developing a 'community of practice' has been emergent, since no such strategy was adopted and the term 'community of practice' has not been officially applied to the team, although our activity has been steered in that direction. Through reading and reflecting on the development of the team, it became apparent that this term was the most appropriate description for what was emerging. In addition rather than these developments being written into operational policy they become part of the unwritten team narrative.¹⁶

In developing a community of practice one advantage of operating in a community palliative care team is that the team is made up of senior, experienced professionals who have a high level of skill in clinical and educational practice and in strategic development. In this team the lead nurse has an inclusive approach to leadership; encouraging innovation and involving the whole team in development work which has facilitated the process greatly. From an early stage in team development, insights from complexity theory applied to management were utilized in team building, e.g. with regular team 'away days' using an 'open space' as a forum for interaction to

¹⁶ Occasionally parts of this narrative will be reproduced in writing, e.g. in the annual team report or in this thesis.

explore service development. In addition the individual skills, interest, dedication and supportive relationships of the team members have facilitated the development of the community of practice. Espousing a complexity approach and recognising the unique emergent local context, has provided a theoretical basis for developing research within the team as described in Chapter-6 (see also Box 7-2, below).

Other factors within the local context have also enabled development of the team. Support for our programmes has been given by senior management within the PCT who regarded the developments positively and have held the palliative care team as a model of innovative practice. Involvement with the university through a Masters programme in palliative care¹⁷ has provided an opportunity for the professional development of several team members. This has enabled working relationships to develop with members of academic staff, further encouraged by the palliative care research group established at the university, which brings academics and local clinical practitioners together. Opportunities of funding for service development and research and a research fellow seconded to the team have enabled the development of the community of research practice. Finally this approach has enabled several research projects to develop in addition to the HCA project in Chapter-6. These are described in Box 7-2 (below).

7.6.3 Benefits and drawbacks of a community of research practice

Developing a community palliative care team as community of practice has benefits for both research and development in community palliative care, and for the team within its wider clinical and professional practice. Conducting research within the team enables the generation of evidence which is directly applicable to the local context and which can be used in local service development. This is illustrated by the findings from the HCA study in Chapter-6 which can now be utilized in developing services.

¹⁷ For which I am co-founder and co-director.

Research undertaken

- 1) *Action research project: Support and education needs of HCAs (Chapter-6)*
- 2) *Narrative study of reasons for palliative care patients calling in an emergency: (Appendix 2)*
- 3) *The experience of patients with end stage renal disease – comparing dialysed and non-dialysed groups: – This study is being undertaken by the specialist registrar who I have supervised and who has worked with the team for 18 months. It has enabled links with the ‘renal failure’ clinical nurse specialist and the palliative care team to grow.*

Research Proposed

- 1) *Exploring the experiences and support needs of junior District nurses: This project is under development, led by a Macmillan nurse as part of a Masters dissertation.*
- 2) *Action research to explore and develop decision making for HCAs: This is proposed to continue once the HCA group can be reformed.*
- 3) *Exploring the experiences of carers (post-bereavement) who have had HCA services in their home: This will enable a comparison with HCA narratives to explore the extent to which HCAs provide psychological and emotional as well as practical support from the carer’s perspective, and to explore the personal costs arising from the home becoming a ‘public space’ for caring.*

Box 7-2- Research undertaken or proposed in the community palliative care team

The local knowledge and clinical skills of practitioners can be used in developing and refining research questions appropriate to the service needs. Practitioners may have easier access to some research contexts than researchers and since they remain in the team to primarily undertake clinical roles they are more likely to be able to negotiate delays within a project if these occur. Traditional research projects may fail because of delays, leading to the project being abandoned. This might have been the case with the study into HCA support needs because of the reorganisations within the PCT. However, despite a period of 18 months when the action research could not proceed, in recent weeks new developments have occurred and the home care

facilitator is now able to resume work with HCAs. We are currently exploring ways in which the action research project may be restarted.

Undertaking research also has benefits for the functioning and professional development of the team. For instance, exploring narratives from patients and from health care professionals in the local context enables new conceptual 'maps' to be constructed which can be of additional benefit in understanding and managing other patients and in working with primary care staff. Research training and experience in the team opens up new areas of inquiry for team member and the support of the 'community' provides an excellent context in which to undertake personal research, such as a Masters dissertation. The outcome of research can be celebrated within the team giving a sense of achievement, for example when papers are accepted for conference presentation. New links can be developed between clinical teams and research institutions, in our case the local medical school. Forming a community of research practice also has benefits for the wider PCT, where we have recently been asked to provide support to enable other teams to undertake research.

All of these positive aspects for research and for team development have an impact on the development of the team as the collective narrative is enhanced and new opportunities arise.

Methodological and practical problems need to be acknowledged in conducting research in this manner. Whilst HCPs' understanding of the contexts in which they practise is a great advantage, they also might find it difficult to take a critical stance, not aware of assumptions they make in their work. Reflexively developing a critical approach and honing skills to explore issues from a different perspective are necessary prerequisites for robust and reliable evidence generation in this context. Working with a researcher on the HCA study in Chapter-6 was an effective way of introducing new perspectives and skills to the team. Attending research meetings, holding journal clubs and presenting at conferences can also be effective ways of enhancing skills.

The major practical problem with developing this model of research is the time needed to undertake projects. The team's core clinical functions still remain and should be the primary focus. Conflicts of interest between research and clinical work

need to be managed carefully, particularly as not all team members will be equally interested or committed to the research.

Research and clinical work progress at different paces, and there can be pressure to move developments on at a pace faster than is conducive to the research project. We experienced this in the HCA project, where there was pressure to put support into place before the exploratory phase was complete. This could have led to difficulty in undertaking the research, resulting in inappropriately developed or targeted interventions.

Times of reorganisation and financial pressure (as currently occurring) can sap the morale of team members and raise questions regarding the value of rigorous assessment and development, when organisational or political decisions, not under the control of the team, can threaten long periods of hard work. These issues need to be carefully considered and the opinions of the whole team need to be explored and valued.

7.7 Conclusion

Palliative care takes a holistic approach to caring for those with advanced illness for whom no cure is possible. Addressing physical, psychological, social and spiritual domains is viewed as being fundamental in the discipline. Since the conditions with which palliative care deals are diagnostically diverse and a large degree of variation exists in the manifestation of disease in these patients, palliative care with its broad remit covers some of the most complex territory within health care. Because palliative care has often developed in a piecemeal and occasionally haphazard fashion within specific localities, a large degree of variation can exist between services in different localities, adding to the complexity.

Locally focused health service research in palliative care allows complex contexts to be explored facilitating local service development. However, local studies can have a wider role in developing the evidence base for palliative care with generalizable or transferable insights being generated by both employing theoretical concepts when interpreting empirical data and generating new theory from the data. I would argue with Waterman et al. (2001) that the development of theoretical insights in

practitioner research is the main feature which distinguishes research from service development.

As argued in Chapter-4, valid RCT evidence in health services research in palliative care is particularly problematic because of the complex context in which these services are delivered. However, a depth realist approach to exploring palliative care is a valid methodology, because it may generate theoretical insights which can be transferred to and built upon in other settings. The structured nature of social reality and the play of power and emotion within social structures are fundamental issues which need to be explored and understood if robust and equitable palliative care services are to be developed.

Narrative research is particularly useful in enabling a depth realist account to be constructed, since complex contexts may be explored through the multi layered structure revealed in the narratives. They are also valuable in constructing maps for exploring complex territory, enabling insights that propositional concepts arising from categorical or quantitative data are unable to provide. In addition, quantitative data will rarely enable power, emotion and social domains to be explored in any depth or detail.

Developing a community of research practice has several specific advantages. Practitioner-researchers may have easier access than non-practitioners to patients and health care professionals and their contextual insights may be particularly valuable in directing research and interpreting findings. They may use evidence directly to develop practice and use insights gained through research to enhance their practice as new conceptual maps are made available to them.

Developing methodologies to explore complex palliative care contexts and enabling practitioners to develop research skills to complement their wide knowledge (both technical and intuitive) could enhance the development of services which are locally appropriate. Any notion of simple solutions to complex problems in this area should be avoided. The process of dying despite the best care will always be difficult for patients and their carers and providing the best care will always be challenging for health care professionals. Developing clinical practitioners' skills for conducting research and employing a critical realist approach to developing a palliative care evidence base are promising strategies.

Why are patients with serious chronic illnesses admitted to hospital?
Participants Information Sheet (1) 1st June 2000

What is the purpose of the study?

People are admitted to hospital for a variety of reasons. Often admission is unavoidable but sometimes it would have been possible for patients to remain at home if more support in the community had been available. This study, performed by Dr Daniel Munday of the Centre for Primary Health Care Studies, University of Warwick aims to discover why people are admitted to hospital and whether there are any additional community services that could have helped them to remain at home.

Why have I been asked to take part?

We are looking for a representative group of patients who, like yourself, have been admitted to the [redacted] Hospital.

What do I have to do if I decide to take part?

You will take part in a brief interview lasting 10 or 15 minutes with Dr Munday. Alternatively we could interview a family member or someone else who has been looking after you, if you prefer. In addition we will be conducting longer interviews with a selection of patients and their relatives or friends. We will ask if you would be prepared to consider taking part in these interviews.

Is what I tell you confidential?

All information about you will be kept completely confidential. Any information, such as name and address, which could be used to identify you will be removed. None of the information you give to us will be given to your GP or any other professional carer in hospital or the community.

What will happen after the interview to the information I give?

Information will be analysed by Dr Munday and Dr Griffiths, an experienced doctor and researcher at Warwick University, who is supervising the project. At the end of the project the results will be presented to [redacted] and other health providers responsible for development of community services. Any examples or quotations given in the results will be completely anonymous.

Who knows about and supports the research project?

[redacted] Hospital NHS Trust, [redacted] Health Authority and Coventry Ethics Committee have agreed to the research project being undertaken. Coventry Health Authority and the [redacted] NHS Postgraduate Medical Office have made research grants available to cover the costs of the project.

Do I have to take part?

You do not have to take part in the study. Your care will not be affected in anyway if you decide not to take part.

Contact for Further Information

If you require any further information about the project please contact Dr Munday at:

The Centre for Primary Health Care Studies

University of Warwick, Coventry CV4 7AL Telephone: 024 7652 4254

Thank you for your time

Why are patients with serious chronic illnesses admitted to hospital? *Participants Information Sheet (3) 1st September 2000*

What is the purpose of the study?

This study aims to discover why people are admitted to hospital and whether there are any additional community services that could have helped them to remain at home.

Why have I been asked to take part?

We are looking for a representative group of patients who, like yourself, have been admitted to the [REDACTED] Hospital.

What do I have to do if I decide to take part?

You will take part in a brief interview lasting 10 or 15 minutes with Dr Munday.

Is what I tell you confidential?

All information about you will be kept completely confidential. None of the information you give to us will be given to your GP or any other professional carer in hospital or the community.

What will happen after the interview to the information I give?

Information will be analysed by Dr Munday. At the end of the project the results will be presented to [REDACTED] Health Authority and other health providers responsible for development of community services. Any examples or quotations given in the results will be completely anonymous.

Who knows about and supports the research project?

[REDACTED] Hospital NHS Trust, Coventry Health Authority (who are funding the research) and [REDACTED] Ethics Committee have agreed to the research project being undertaken.

Do I have to take part?

You do not have to take part in the study. Your care will not be affected in anyway if you decide not to take part.

Contact for Further Information

If you require any further information about the project please contact Dr Munday at:

The Centre for Primary Health Care Studies

University of Warwick, Coventry CV4 7AL Telephone: 024 7652 4254

Thank you for your time.

Appendix 1.3 – Abstract of Poster Presentation at the Narrative Research Conference, BMA, London. 4th – 5th September 2004

Ethical Issues arising from Narrative Research in Palliative Care

Daniel Munday¹, Frances Griffiths¹, Mark Bratton.² (¹Centre for Primary Health Care Studies, ²Chaplaincy, University of Warwick.)

Introduction: Research involving palliative care patients presents ethical issues which need special consideration. However, narrative research enables their experiences to be understood and used to inform the development of appropriate health care services.

Aim: Examination of ethical issues arising alongside the formal collection of narrative data of patient's experiences regarding emergency admission to hospital beds.

Methods: A semi-structured interview study was conducted with patients who had been admitted as emergencies to district general hospital beds. A physician experienced in palliative medicine undertook patient recruitment and interviews. Reflection on ethical issues arising was continuously performed and recorded in a research diary.

Results: Initially three patients, although keen to recount their experiences, found the standard information and consent process cumbersome and threatening. This precluded inclusion of the narrative accounts of these patients in the study. Subsequent adoption of a discursive information and consent process supported by a simplified research information sheet was well received by patients, who invariably were keen to recount their experiences. Thirty two patients were subsequently recruited, their narratives providing rich accounts of events leading up to admission. These revealed complex reasons for admission and decision making based on previous experience of and personal confidence in available services.

Conclusions/ implications: Standard research information and consent processes with palliative care patients may prove stressful thus making them unethical. Excluding such patients from research however, denies the patient a voice, disempowering and barring them from influencing service development. This paper will explore a framework for giving information and gaining consent in narrative based research using a discursive method.

Appendix 2: Investigating community palliative care using a ‘critical incident case study approach’ – A feasibility study: draft report

II.1 Introduction

Emergency hospital admission of palliative care patients represents the end of a chain of events which occurs in the community, normally starting with a clinico-social problem. Whilst it is not clear how many urgent calls to health care professionals in the community end in hospital admission, it is likely to be the minority. In addition for these patients any call is potentially complex and a challenge for the attending professional, whatever the outcome. This appendix briefly presents the methods and some of the results emerging from a study into unscheduled care of palliative patients in the community. It illustrates the utility of involving practitioners in undertaking research and provides triangulation for the emergency admission study (Chapter-5).

Since the emergency admissions study (Chapter-5) had only included patients who had been admitted to hospital, we decided to undertake a study which was not restricted to these patients, but include those in whom there had been other outcomes. The study was also designed to explore the experiences of patients, their carers and health care professionals (HCP) surrounding a particular incident in which a community service had been called to attend the patient. Since the study was planned at the time when the new GP contract (2003) was being established, with the potential for radical change in how out of hours primary care was to be delivered, it was considered important to explore this broader context to enable us to undertake appropriate service development within the PCT.

In exploring these incidents from multiple perspectives we hoped to gain insights into the contextual issues which affected the outcome of calls for ‘unscheduled’ care in palliative patients in the community.

Since we wished to gain detailed a description of the events, it was envisaged that interviews would need to be held as close to the event as possible. HCPs dealing with many individual cases are likely to quickly forget details of an encounter. Whilst they have access to case notes to aid recall, reliance on these alone would restrict the ability to describe important contextual factors given the highly reduced nature of the medical history. In addition to descriptions of the clinical issues addressed, we hoped

to have a description of the contingent issues affecting the encounter, e.g. what was the HCP involved in when the call was received, how did they assess the urgency of the call, how did they arrange their programme to deal with it, did they have any information about the patient? How effective this approach would be was uncertain. Therefore we decided to conduct this as a feasibility study taking care to record the outcomes of the process of the research as well as the narratives emerging from case studies.

II.2 Aim

The study was designed to address the following research question:

1. Is a critical incident case study approach feasible for investigating unscheduled care in palliative care patients in the community?

In understanding community palliative care in this context it was important to be able to answer the following questions:

2. What type of incident leads to a call for unscheduled care for palliative care patients in the community?
3. How are these incidents managed?
4. How do narratives of patients, carers and health professionals regarding the same event concur and how do they differ?

Answering these questions would then give insight to the practical question:

5. How might appropriate services to provide unscheduled community palliative care be developed?

II.3 Method

As in the Emergency Admissions Study (Chapter-5) the critical incident formed the focus for the narrative account for each participant. Narratives from as many individuals involved in the incident as possible were included: the patient, informal carer and any health care professional, including the GP, DN, Macmillan nurse, health care assistant etc. Documentary evidence such as case notes and computer records were accessed and recorded in field notes if possible.

Inclusion criteria

Any adult palliative care patient (as defined in the emergency admission study Section 5.3.2.1 page 172) in the community for whom there had been an urgent call to a health care professional was eligible for inclusion. We planned to recruit patients from a variety of sources: DN, Macmillan nurse, out of hours GP or following hospital or hospice admission. When the patients were identified, if they were considered fit enough to be interviewed, they were approached by their DN or Macmillan nurse and asked to consider taking part. The patient and carers were given an information sheet and invited to ask any further questions they might have had. The DN or Macmillan nurse contacted the patient again after 24 hours to check whether they had agreed to take part.

The interview process

The interviews had a similar structure to those undertaken with patients in the emergency admissions study (Section 5.4.2.3 page 184), with the events being recorded in a time sequence. For the patients and carers important aspects were: the problem faced, the action taken, any other possible actions considered, the outcome and subsequent events following the incident. For the HCPs we explored how the event was dealt with, but also the contextual factors, e.g. their recall of when the call was received, how they prioritised the consultation, other work being undertaken at the time and what information about the patient they possessed.

Since several perspectives for the same event were being examined we considered it advisable for the accounts to be collected and recorded by different researchers, with an estimated maximum of five interviews per patient being conducted. It was possible that hearing the incident from one perspective would affect how a subsequent interview was conducted and that patient confidentiality could be threatened.

It was not feasible for each interview to be conducted by a separate researcher, however, we considered it a reasonable compromise for one researcher to interview patients and informal carers and a second researcher to interview the HCPs involved. This also enabled reassurance to be given to the patient and carer that confidentiality would be maintained when they gave their consent for HCPs to being approached and interviewed.

I conducted the patient and carer interviews first and the HCP interviews were undertaken by a second researcher following this. Interviews were audio recorded using the Olympus DM-10 and transcribed verbatim.

Analysis

The critical incident was taken as the unit of analysis, as for the emergency admission study, however in this case there were several parallel accounts to be constructed. The text of patient and carer's narratives were taken as the basic accounts since they were the principle protagonists for the incident, with the HCPs accounts being linked in to these at certain points. The objective of the analysis was not to judge between accounts in order to reach a 'true picture' of what had happened, but to explore how the narratives through time form and 'interweave' and to take account of the contingencies affecting each of the narratives. In addition themes emerging between case studies were noted.

The data from this study reveal a complex picture with many interlinking issues on different levels. For this reason the analysis was undertaken using the immersion/crystallization rather than an inductive technique. Detailed maps of the cases were constructed to elucidate these complex interacting processes.

Feasibility notes on the method

The following questions regarding the feasibility of the method were considered:

- Is it possible to recruit patients via district and Macmillan nurses and via out of hours services; how effective and costly in time is this and is it acceptable to the health professionals and patients/carers?
- Are patients/carers prepared to consent to their health professionals being contacted?
- Are health professionals accessible for interview within a reasonable time frame?
- Was access to documentary evidence such as clinical records, nursing records, possible and how were blocks to accessing such information overcome?
- Did the process and results of interviewing indicate appropriate interview arrangement and styles including face to face vs telephone interviewing, length of interview, optimum time after the critical incident for interview to take place?

- Did the research method generate sufficient detail of data that could be combined for analysis of each incident?
- How might this research method be refined to increase the quality of the data collected and the acceptability for patients, their carers and health professionals involved?
- Did any ethical issues arise that had not been considered prior to undertaking the research?

Before the study commenced, through discussions within the research group (i.e. myself as principle investigator, co-researcher and PhD supervisor), it was decided that using the term ‘critical incident’ was likely to cause difficulties. Clinical work being complex and replete with uncertainty frequently leads to unforeseen outcomes some of which will be seen, sometimes unjustifiably, as mistakes or failures. For this reason in the process of clinical governance, ‘critical incident’ has a meaning laden with pejorative and inquisitorial undertones. Palliative care clinical work in the community has attracted particular scrutiny and is frequently infused with a moral imperative. Current interest in end of life care, whilst being important in highlighting the needs and plights of dying patients in the community, also has the potential for making HCPs feel ‘under siege’. Thus the term ‘critical incident’ was likely to lead to misunderstanding on the part of HCPs, who were relied upon to both recruit patients and to be interviewed themselves. For this reason the title of the study was altered to ‘Narrative case study’.

II.4 Results

Cases recruited

The challenges involved in conducting this study meant that whilst we had planned to undertake ten cases studies we have only able to complete six so far. The six cases were recruited from a variety of sources (Table II – I):

Id	Cases Studies	Description	Interviews	Notes on Method and Feasibility
1	52 year old man Carcinoma of Pancreas	Severe pain on a Saturday afternoon. Called DN and GP visited. Problem continued intermittently until Monday (Bank Holiday) with several calls. Admitted to hospice on the Tuesday following for symptom control	Patient Wife DN Macmillan nurse On Call GP	<i>Recruited after admission to hospice</i> Patient and his wife were keen to be interviewed in the hospice 5 days after the incident. The DN and Macmillan nurse were interviewed within two weeks of the incident. The GP was more difficult to contact as he worked part time. He was interviewed 5 weeks after the incident
2	47 year of lady Metastatic Cancer of Breast	Severe pain on a Sunday having been discharged from oncology ward on Friday following chemo-therapy without morphine for breakthrough pain.	Patient Husband DN On call GP	<i>Highlighted by the On call GP who visited</i> Patient and husband were interviewed 2 weeks after the incident. The GP was interviewed two days after the patient and the DN one week after.
3	59 year old man Mesothelioma	Called GP at 8:30 am on a weekday morning with severe pain. GP called the Macmillan nurse to ask her to review.	Patient and daughter together Macmillan nurse	<i>Recruited by Macmillan nurse involved</i> The patient's own GP refused to be interviewed. The DN agreed but never made herself available despite numerous requests from the research assistant
4	65 year old lady Metastatic Carcinoma of Cervix	Severe pain in leg on a Saturday night. Health Care Assistant (HCA) needed to call for help. 2 GPs visited through night and the next morning a Macmillan nurse arranged for her to be admitted to hospital.	Patient HCA Night DN On call GP Macmillan nurse	<i>Highlighted by Macmillan nurse involved</i> The patient was interviewed in hospital 5 days after the incident. The GP, DN and Macmillan nurse were interviewed within 2 weeks of the incident and the HCA within three weeks. This was the first case for which the Macmillan nurse conducted interviews. Negotiating access seemed much more straight forward.
5	82 year old man Carcinoma of Prostate and Heart Failure	Very frail. Nausea and vomiting a problem over a weekend. Wife called NHS direct and a GP visited.	Patient and wife together Patient's own GP.	<i>Highlighted by Macmillan nurse</i> The patient and wife were interviewed one week after the incident and the GP interviewed within two weeks. It was not possible to interview the visiting GP as it was unclear from the GP records who this had been (it was out of hours) and the visit was not recorded at the out of hours centre.
6	74 year old lady. Carcinoma of Ovary	Nausea and vomiting and abdominal pain on a Saturday morning. Out of hours service called who passed on call to the Macmillan nurse, who arranged for a syringe driver to be set up. Three days later was admitted to the hospice for further management.	Patient's son Macmillan nurse DN	<i>Highlighted by Macmillan nurse</i> The patient's son was interviewed 5 days after admission to the hospice and the Macmillan nurse and DN within 2 weeks. Although an interview with the patient was planned she deteriorated in the hospice and died before this was undertaken.

Table II – I – Summary of cases recruited in the critical incident case study

Two further patients were identified but recruitment was not possible since one declined inclusion as she felt too unwell and the second whilst the patient's daughter was keen to take part (the patient was cognitively impaired and therefore an interview was not possible) the patient died before interview and it was considered inappropriate to continue.

Findings

Patients and Carers

The narratives obtained illustrated the complex nature of these incidents. Even the most straight forward of the cases (Case-2) with the need to obtain a prescription for morphine, involved a number of individual steps. The husband had to decide who to call and initially tried the DN. He was told to contact the GP to get the number for the 'out of hours' service. On contacting the out of hours service he was asked if his wife could come down to the centre but he explained that this was not possible because of his wife's condition. The out of hours GP paid a visit within 45 minutes and gave a prescription for oral morphine. The husband then had to take the prescription to a pharmacy on a Sunday afternoon which the GP told him was open.

The linearity of this process belies the complexity underlying it. The husband was not sure who he should call. He and his wife were concerned because they had previously had a poor experience with out of hours services; on more than one occasion needing to go to the out of hours centre and waiting several hours and on another being sent to the emergency admissions unit (EAU) and spending several hours there. The husband had apparently spoken to his wife's DN (according to his wife), but when the DN was interviewed she said she did not take the call that day and only got to know the patient subsequent to the incident. There was no mechanism for finding who had taken the call. The answer machine at his wife's GP practice instructed the husband to call a telephone number in a town 10 miles away. This was in fact the call handling centre, but the patient was under the impression this is where the GP came from. Both the patient and her husband were very satisfied with the result on this occasion, although the husband recounted how difficult and unpleasant getting help had been in the past.

‘A few times we’ve been backwards and forwards and that’s been a nightmare and that’s why she tends to put it off. She waits until it’s really bad and then tells me that it’s too bad and we’ve got to do something now rather than, “I’ll be alright, I’ll be alright”. This time there was nothing like that she’s sorted; and she wouldn’t, if it goes like that every time when we come across it again we don’t mind. But it’s the prating about at other times but, yeah this was alright, this was because, it was a Sunday we thought we were gonna end up at the EAU again and she was dreading that, because she does stress, she gets one end up and makes things worse. (*Case 2 husband*)

In all cases there was a difference in the narrative between respondents either about who had been called, who had arrived at what point and what the outcome had been; as the complexity of the incident increased these differences seemed to become more pronounced. This was particularly noticeable in Case 1 and Case 4 in which several hours and numerous telephone calls and visits ensued during the incident.

Most patients and carers had several agencies which they could call. The wife of the patient in Case-5 had been advised by her granddaughter who was a nurse to phone NHS Direct and she gave her the number to call. What delighted the wife about this service was that she spoke directly to a HCP rather than having to listen to a message on an answer machine.

All patients were keen to avoid being admitted to hospital. As with Case-2, patients and their carers would go to some lengths to ensure that this would not happen. The wife of the patient in Case-1 explained how she had to persuade the on call service that her husband should not go the EAU.

Yes and the time before that I said “no I don’t want to go down there [EAU] because it’s not good for [husband] he just needs pain relief”. Because you know they don’t specialise in cancer there and you just need to be with people that know, you know like a place like this [hospice] really or a special ward. It’s having to go through the whole process you know of explaining on the phone and then the doctor phoning you back and saying is he still in pain and you’re saying “yes” you know and then waiting for him it’s just a nightmare really (*Case 1 wife*).

Having contact with someone who knew the patient and the situation was highly valued by all of the patients and carers as illustrated by the son of the patient in Case-6

‘When the Macmillan nurse phoned, my father’s face lit up because it was not just somebody coming it was somebody who knew her’ (*Case 6 son of patient*).

Health Care Professionals

Often several HCPs were involved with a single incident. The DNs and Macmillan nurses described communicating with each other and with the hospice or the oncology ward. It was half way through the study that the seven-day-week Macmillan service was set up. The DN in Case-1 (before the service) described talking to the Macmillan nurse on the day before the incident (Friday) about the patient. She reiterated the preference for a weekend service, as highlighted in the HCP key informant interviews (Section 5.5.3.1 page 216). Case-4 and Case-6 received the weekend service. The patient in Case-4 was admitted to hospital as the Macmillan nurse felt the patient needed investigation¹, whilst the patient in Case-6 remained at home after symptom control advice, being admitted to the hospice several days later. The GPs interviewed did not describe working collaboratively with nurses, although the GP in Case-1 did express the wish to have access to a specialist palliative care service. All GPs described being under great pressure when working out of hours when they found prioritising cases challenging. Calls were ordered more in terms of where they were in the City rather than on the basis of patient need. If patients were not able to wait they were told to go to EAU.

Notes on the feasibility study

During the period of the study two cases were rejected for inclusion (before the patient was contacted) because both of these were incidents in which complaints may have been forthcoming. The cases had in fact been highlighted by a Macmillan nurse for the very reason that they illustrated ‘extremes’. It was judged important however that the cases in the study were not of this type as the research and the clinical

¹ Her nephrostomy tube had fallen out earlier in the week and her present pain could have been related to that.

governance investigation could become confused and also it was unlikely that HCP would be happy to be interviewed, or if interviewed they would be reluctant to give an unrestricted account of their experience. The possible quasi-judicial inference drawn by potential HCP participants arising from the study design may have precluded some from taking part both in the interview and recruitment process, in spite of careful explanation that we recognised the complexities involved and were in no way seeking to highlight poor practice. This anxiety amongst HCPs was recognised in a discussion with a senior community nurse on the slowness of recruitment. Her perception was that community nurses working out of hours may be reluctant to highlight patients for the study because this might be seen as an implicit criticism of the day time DN service.

It did prove difficult to achieve rapid access to HCPs for interview. Few HCPs directly declined to be interviewed, although the GP in Case-3 definitely did so. The normal course was a tentative agreement, followed by difficulty in finding a convenient time for the interview. On several occasions HCPs were contacted, but failed to return calls at the request of the researcher. This problem was mitigated to some extent when there was a change in researcher part way through the study - a research assistant (RA) with a social science background who was involved in the first three cases was replaced by a Macmillan nurse.

The Macmillan nurse used her considerable experience to gain access to HCPs, for example dropping in on DNs in their bases and contacting GPs at the times she judged they would be available for discussion. She was also able to reassure DNs more strongly than the RA had been that the study was not quasi-judicial and was therefore able to encourage recruitment into the study. Finally, she was able to access computerised records in the out of hours centre, which enabled us to identify the relevant HCPs who had dealt with a particular case. The Macmillan nurse had experience in conducting research interviews with key informants in the study presented in Chapter-6 (Section 6.4.1 page 248).

II.5 Discussion

The six case studies undertaken in this project illustrate the complexities involved in a variety of scenarios in which unscheduled care was needed for palliative patients in

the community. They illustrate that even relatively simple problems can produce high levels of stress for the patient and their carers. For HCPs little knowledge of the patient and a high pressure of work can mitigate against providing high quality care. Marked differences can exist between the patient and carer's memory and understanding of the incident and that of the HCP. The patient and carer's narrative focused more on the emotional and practical aspects of the incident, whilst the HCPs accounts tended to focus on clinical issues and on interpreting why the patient had a particular problem or need.

These cases do not represent an exhaustive set of unscheduled care situations for palliative patients in the community. They must therefore be seen as illustrative rather than presenting a comprehensive description. However these case studies do illustrate important structural issues which can be addressed in attempting to deliver a robust service. Since the GPs in the study appeared unaware of the specialist provision available to them we have been addressing this issue with them and the study has confirmed the importance of having a seven-day-week Macmillan service.

The findings for this study have been useful for triangulation with the emergency admissions study. They support the finding that patients and their carers will select the professional or agency with which they have a personal relationship, who will be available and from whom they judge the most acceptable outcome will be forthcoming. This has been particularly valuable since the interviews with patients and carers were longer than those in Chapter-5 and were audio recorded. Similar findings in both studies help to assure the validity of the original bedside interviews.

This study has been challenging to undertake, not least because of the sensitivities of HCPs to discussing their practice. It seems that there are distinct advantages in using health care professionals as researchers for a study such as this. For future research we plan to build on the insights we have gained from this feasibility study.

Appendix 3.1 – Abstract for presentation at EAPC Congress, Aachen, April 2005

Action Research: A feasible method for service development in palliative care?

Daniel Munday, Kashifa Mahmood, Marion Corroon, Frances Griffiths

Introduction: The complex nature of community palliative care makes action research a potentially valuable approach for service development. By this method health professionals engage in research using a cyclical process of reflection, action and evaluation to explore and enhance local practice. We present initial findings of an ongoing study in which professionals and researchers are using this approach to develop a palliative care service.

Aim: To explore the feasibility of using action research to develop a home care nursing service (HCNS) provided by health care assistants (HCA).

Methods: The work of the HCNS in one year was surveyed retrospectively followed by key informant interviews to explore issues for service improvement. Results were presented to a focus group of relevant stakeholders to allow a developmental strategy to emerge. Continuous reflection regarding the research process was made at a theoretical and practical level to assess the feasibility of its application to palliative care.

Results: Findings revealed that whilst the HCNS was highly valued and effective, organisational deficiencies and lack of professional support for HCAs existed. The solution of employing a senior nurse as co-ordinator is currently being developed.

Process issues identified included: conflict between time spent in research and service activities, differing time-scales for service development and research, and failure to engage HCAs sufficiently in the project.

Conclusions: Action research may provide a robust and transparent model for service development. However conflicts between service and research requirements may compromise the rigour of the method and power differentials may threaten its emancipatory nature. Continuous reflection and flexibility of the process are vital to its success.

Appendix 3.2 – Letter inviting health care assistants for interview

PCT letter headed paper

Dear [NAME]

Action research in collaboration: Developing palliative education and support for health care assistants using a participatory approach

I am a Macmillan Palliative Care Facilitator developing an educational programme for support workers caring for patients with complex needs in the home setting. My role is underpinned by an action research project in collaboration with Dr Dan Munday Consultant in Palliative Medicine and [REDACTED] Research Fellow at Warwick University. The aim of this study is to identify how best to design an educational programme that will strengthen family support workers in coping with the service needs and demands of very dependent patients and their families.

As part of the action research project, [REDACTED] and I would greatly appreciate an opportunity to interview you about your perceptions and the difficulties that arise in attending to such patients in the community. Your experiences and views will be important to shaping an educational programme that matches the vocational and training needs you express. The interview will be recorded and transcribed so that we can analyse it. All references to you will be removed from the interview transcript and anything you say will remain entirely confidential.

I would be most grateful if you were able to spare some time to be interviewed and will contact you soon to arrange an appointment. If you have any questions about the interview or the project, please don't hesitate to ask.

Yours Sincerely

[REDACTED]
Macmillan Palliative Care Facilitator

Appendix 3.3 – Health care assistant participant information sheet



THE UNIVERSITY OF
WARWICK

Participant Information Sheet

Action research in collaboration: Developing palliative education and support for health care assistants using a participatory approach

An action research approach is being used to conduct a needs assessment of the support and development requirements of health care assistants (HCAs) attending to terminally ill patients at home. The results will be used to shape the role of the Home Care Facilitator recruited to deliver a professional development and support programme responsive to HCA priorities and preferences.

You are kindly requested to be interviewed in a research study undertaken by Dr Dan Munday, Consultant in Palliative Medicine; [REDACTED], Home Care Facilitator, and [REDACTED], Research Fellow from Warwick University. The following sections will explain the purpose of this study and how your views may inform an understanding of the design of an educational programme that is relevant and appropriate to meeting the needs identified. Please do not hesitate to contact us should you require further information.

Thank you

What is the purpose of the study?

The present study aims to enhance the quality of palliative care services provided to patients by strengthening the educational knowledge accessed by HCAs. The objective of this interview based study is to provide insight into subject areas deemed relevant by HCAs so as to ensure that the areas

selected for inclusion in an educational programme are rooted as much as possible in the ideas expressed by participants in this study.

Reflecting on the level of organisational support being offered is considered an important element of this study since it may impact on the effectiveness with which members of staff are able to discharge their responsibilities. The interviews seek to ascertain information on the level of support desired and currently received by HCAs. The ideas, comments and suggestions of HCAs will then be presented for the action research group to consider in terms of which support needs identified during the interview process can be responded to within the practical constraints they are subject to.

The project focuses on raising awareness of the significant contribution that HCAs make to caring for very ill patients in the community approaching the closure of life. A key objective is to highlight the range of issues that arise for HCAs who are providing care in the challenging setting of patients' homes and to review how adequately staff are guided and equipped to work in such circumstances. Acknowledgement and appreciation of the part played by HCAs in monitoring and implementing patient care may create opportunities to enhance the skills and confidence of staff providing services in this field.

Who is organising and funding the research?

The research is being organised by Dr Dan Munday, Consultant in Palliative Medicine and Honorary Clinical Senior Lecturer based at [REDACTED] Primary Care Trust and the University of Warwick. The project is funded by the [REDACTED] Cancer Network and ethically approved by [REDACTED] Primary Care Trust to which you are affiliated.

Do I have to take part?

It is voluntary and you may decide whether or not you wish to participate. If you do decide to participate you will be asked to sign a consent form indicating your agreement to be interviewed.

What do I have to do?

You are being invited to share your thoughts, perceptions and experiences from practice on how you support palliative patients at home during the dying phase. You will be contacted by telephone to arrange an interview at a time convenient for you. The interview may take place either in the Palliative Care team office [REDACTED] or your home address whichever you prefer. The duration of the interview will be approximately between 30 minutes to an hour. This interview will be audio-recorded with your permission so that it may be analysed.

How will confidentiality be maintained?

All information that is collected during the course of the research will be kept strictly confidential and will only be accessed by Dan Munday, [Research Fellow] and [Home Care Facilitator]. Audio-tapes of the interview will be stored securely and all recordings will be destroyed at the end of the study. Your name will not be transcribed or used when discussing the research

material. Any identifying details in your transcript will be removed so that you cannot be recognised.

An action research group which convenes at regular intervals has been formed to identify and discuss how this project could be used to establish a support structure for HCAs. The group comprises HCAs, a Consultant, Home Care Facilitator, District and Macmillan nurses and a Research Fellow. Themes in the overall data emerging from the interviews may be introduced at these meetings for general discussion but individual informant details will remain entirely confidential and will not be released to the action research group.

What are the possible disadvantages of taking part?

It is most unlikely that you will be inconvenienced by taking part in this research project. However, if you have any concerns about any aspect during the course of this study you can write to Dr Dan Munday, Division of Health in the Community, University of Warwick, Coventry, CV4 7AL, or contact him by telephone on 02476 522536.

What are the possible benefits of taking part?

The information you give will be invaluable in helping to address the professional and personal development needs of HCAs. Education and formal support to HCAs will enable the aims of this project to be realised which is ultimately to enhance the quality of care provided to palliative patients.

What will happen to the results of the study?

The results may be published in medical or social science journals or presented at conferences so that others can benefit from the points learned about using a collaborative approach to develop services through the involvement of staff in decision making. Any examples or quotations given in the results will be completely anonymous.

Please contact at the following address if you require further information:

██████████, Home Care Facilitator
Macmillan Palliative Care Team

████████████████████
████████████████████
████████████████████

██

Health Care Assistant Interview Guide 01- 08-2005	
<p>Interview questions</p> <ul style="list-style-type: none"> • Briefly describe your range of duties? • Did previous <i>nursing experience</i> help in your current job, if so how? • Was it your choice to become a bank or permanent staff member? <p>Training</p> <ul style="list-style-type: none"> • If induction rec'd ask what it comprised? • What were the most/least useful aspects? • What specific training have you had in palliative care? • Do you feel you have any training needs, if so what? • How did you perceive your NVQ training (extent of usefulness if rec'd?) <p>Support</p> <ul style="list-style-type: none"> • What forms of support would help you in your job (formal/informal)? • Do you have a close working relationship with any staff in particular? <p>Decision making</p> <ul style="list-style-type: none"> • Give an ex. of a care situation where you had to look after a dying patient at the end of life and describe the type of decisions you have had to make? • Who do you normally contact first if there's a problem during your shift? • How difficult or easy is it to follow the rules when trying to give good care? • How does it make you feel when the family ask for help with something you're not really supposed to do? • Have there been any incidents that required you to report it? • How valued do you feel you are? • What makes you stay in the job? 	<p>Supplementary</p> <p><i>(Where have you worked previously in caring roles)</i></p> <ul style="list-style-type: none"> • Support network (examples) Attendance at family support workers meetings?, mentoring, supervision, shadowing nurses, courses (eg NVQ training). • Which aspects of the job are the most rewarding? • Which aspects are most worrisome? • Why did you make that decision? • What else could you have done? • What was the outcome, consequences? • Any guidance to help in those situations? • Difficult situations (eg lifting, medication)? • Is there any one else you could have called? • What happened afterwards? <p>Ask about medication issues Lifting and handling</p>

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