What influences referrals in community palliative care services? A case study.

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What influences referrals within community palliative care services?
A case study.

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Table of contents

Table of contents 2
List of tables 6
List of figures 7
List of appendices 8
Abstract 9
Declarations 10
Acknowledgements 12
The author 13

Chapter one  Introduction to the study
1.1 Introduction 16
1.2 Defining palliative care and its provision 17
1.3 Equitable access to care 19
1.4 The policy background to the study 21
1.5 Summary 23

Chapter two  Literature review
2.1 Review strategy 25
  2.1.1 Search strategy 25
2.2 Critically appraising the studies reviewed 27
2.3 The structure of the literature review 29
  2.3.1 When are patients referred to community palliative care services? 29
  2.3.2 How many patients are referred to community palliative care services? 44
  2.3.3 Which patients are referred to community palliative care services?
    2.3.3.1 Demographic information 62
    2.3.3.2 Social information 67
    2.3.3.3 Medical information 70
    2.3.3.4 Summary 73
  2.3.4 What reasons are given for referral to community palliative care services, and who makes these referrals? 104
  2.3.5 What factors act as barriers to or facilitate referrals from professionals to community palliative care services?
    2.3.5.1 Professional factors affecting referrals 113
    2.3.5.2 Organisational factors affecting referrals 118
    2.3.5.3 Patient factors affecting referrals 119
  2.3.6 What are patients’ and carers’ views on referral to community palliative care services? 139
2.4 Summary of literature review 153

Chapter three  Research methods – choice of method
3.1 Introduction 158
3.2 Research aims and objectives 158
3.3 Study design 160
  3.3.1 Choosing an appropriate design 160
6.2.1 Social reasons for referrals to community palliative care services 224
6.2.2 Psychological reasons for referrals to community palliative care services 229
6.2.3 Physical reasons for referrals to community palliative care services 234
6.3 Referral issues 237
6.3.1 Appropriateness of referrals 237
6.3.2 Controlling access to services 242
6.3.3 Reluctant referrers 244
6.3.4 Timing of referrals 246
6.3.5 Patients’ characteristics 250
6.3.6 Patient choice: the perspective of professionals and patients 253
6.4 Summary 256

Chapter seven  Professionals’ perceptions of their own roles in palliative care

7.1 Introduction 259
7.2 Autonomy and self management 259
7.3 Ownership 265
7.3.1 Building a relationship with patients and families 271
7.4 Expertise in palliative care 278
7.5 Workload issues 282
7.6 Status of palliative care work 288
7.7 Summary 292

Chapter eight  Working with other professionals in palliative care

8.1 Introduction 295
8.2 Knowing about other services 295
8.3 Negotiating team roles 301
8.3.1 Concepts of teamwork 302
8.3.2 Negotiating and building relationships between professionals 307
8.3.3 Team leadership and the key worker role 311
8.4 Judging other professionals 318
8.5 Summary 328

Chapter nine  Discussion and conclusions

9.1 Introduction 331
9.2 Review of the thesis 331
9.3 Theoretical propositions 333
9.4 Discussion 336
9.4.1 Professional judgement and autonomy 336
9.4.2 Collaboration, teamwork and partnership 342
9.4.3 Professional relationships 345
9.4.4 Equity 350
9.5 Critique of research 352
9.6 Recommendations for further research 357
List of tables

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Examples of terms used in the literature review search strategy</td>
<td>26</td>
</tr>
<tr>
<td>2.2</td>
<td>Studies investigating when patients are referred to community palliative care services</td>
<td>34</td>
</tr>
<tr>
<td>2.3</td>
<td>Time from referral to death for patients referred to different palliative care services.</td>
<td>30</td>
</tr>
<tr>
<td>2.4</td>
<td>Studies investigating how many patients are referred to community palliative care services</td>
<td>50</td>
</tr>
<tr>
<td>2.5</td>
<td>Summary of the themes of research investigating which patients are referred to community palliative care services</td>
<td>75</td>
</tr>
<tr>
<td>2.6</td>
<td>Studies investigating which patients are referred to community palliative care services</td>
<td>85</td>
</tr>
<tr>
<td>2.7</td>
<td>Studies investigating the reasons given for referral to community palliative care services and who makes these referrals</td>
<td>107</td>
</tr>
<tr>
<td>2.8</td>
<td>Studies investigating what factors act as barriers to or facilitate referrals from professionals to community palliative care services</td>
<td>122</td>
</tr>
<tr>
<td>2.9</td>
<td>Studies investigating patients’ and carers’ views on referral to community palliative care services</td>
<td>144</td>
</tr>
<tr>
<td>3.1</td>
<td>Advantages and disadvantages of different research designs to answer the research questions posed in this study</td>
<td>160</td>
</tr>
<tr>
<td>4.1</td>
<td>Proposed methods of data collection</td>
<td>179</td>
</tr>
<tr>
<td>4.2</td>
<td>Summary of numbers of respondents interviewed for the study</td>
<td>191</td>
</tr>
<tr>
<td>4.3</td>
<td>Case study tactics for the four design tests</td>
<td>204</td>
</tr>
<tr>
<td>5.1</td>
<td>Index of comparative need for the three case study sites</td>
<td>219</td>
</tr>
<tr>
<td>5.2</td>
<td>Summary of specialist palliative care provision within cases studied</td>
<td>220</td>
</tr>
<tr>
<td>6.1</td>
<td>Use of the reasons for referral code within the thematic framework</td>
<td>224</td>
</tr>
<tr>
<td>8.1</td>
<td>Numbers of positive and negative comments made about community palliative care staff within each case study site</td>
<td>319</td>
</tr>
</tbody>
</table>
List of figures

4.1 Diagram depicting the case study design and method 176
4.2 Flow chart showing data collection in case study A 192
4.3 Flow chart showing data collection in case study B 193
4.4 Flow chart showing data collection in case study C 194
4.5 Components of data analysis: interactive model 197
4.6 Key features of framework analysis 198
Appendices

Appendix 1  Example of literature review search strategy  396
Appendix 2  Table of contents alerts for the literature review  398
Appendix 3  Research quality scoring system  399
Appendix 4  Letter of invitation to professional respondents  401
Appendix 5  Response sheet from professional respondents  402
Appendix 6  Information sheet for professional respondents  403
Appendix 7  Letter of invitation to non professional respondents  406
Appendix 8  Information sheet for non professional respondents  407
Appendix 9  Consent form for professional respondents  410
Appendix 10 Information for health care professionals about recruiting patients for the study  411
Appendix 11 Letter of invitation to patients  413
Appendix 12 Response sheet from patients  414
Appendix 13 Information sheet for patients  415
Appendix 14 Consent form for patients  418
Appendix 15 Data extraction form to use with patient’s notes  419
Appendix 16 Topic guides for interviews  421
Appendix 17 Documentary evidence collected from the case study sites  426
Appendix 18 Thematic framework used for coding data  429
Appendix 19 Extract from a coded interview  433
Appendix 20 Example of part of a chart  435
Appendix 21 Population based needs assessment for palliative care  439
Abstract

Equity of access to healthcare services is a concept which underpins current UK health policy. However evidence suggests that this is not achieved within community palliative care. Referrals can be tardy or not made at all. Most literature describes inequality in service utilisation, but does not aid understanding of why such inequalities exist. There is little research exploring the processes underpinning referral making rather than the outcomes of referrals such as service utilisation.

The aim of this research was to investigate the influences on referral decisions made within community palliative care services. A qualitative case study strategy was chosen as the research approach as it provided a framework for facilitating the incorporation of multiple perspectives in a complex context, in a field where there has been little previous research, and where there is little theory to guide the investigation. Three cases (Primary Care Trusts) were studied. Data collection used multiple methods (interviews, observation and documentary analysis, as well as mapping and profiling the palliative care services provided within the cases) from multiple perspectives (general and specialist palliative care professionals, managers, commissioners and patients). Detailed data analysis followed a framework approach, comparing and contrasting patterns within and across cases with existing and developing theoretical propositions.

Two core influences on the way health care professionals made referral decisions were found. First, their perception of their own role in providing palliative care. Autonomous professionals made independent judgements about referrals, influenced by their expertise, workload, the special nature of palliative care and the relationship they developed with patients. Second, their perception about those to whom they may refer. Professionals needed to know about services to refer, and then made a complex judgement about the professionals involved and what they could offer the referrer as well as the patient.

These findings indicate that many more factors than an assessment of patients’ clinical need affect referrals within community palliative care services. It appears that personal, inter-personal and inter-professional factors have the potential to shape referral practices. It may be that the combination of these factors has an influence on equitable access to community palliative care services. Practitioners could be more explicit about referral or non-referral rationales, and policy makers take account of these complex influences on referrals rather than just mandating change.
Declaration

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Published work

Some aspects of this research have been presented or published during the conduct of the study, and are listed below. All are the original work of the author. Some of the discussion presented in Chapter 3 draws on work previously written and published by the author:
Other work and presentations based on the research presented in this thesis:


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I am grateful to many people for their involvement, support and encouragement during my studies.

I am grateful to the Department of Health for funding the award which gave me the time I needed to study. Thanks must also go to my supervisors, Ann Caress, Carolyn Chew-Graham and Chris Todd who have patiently guided me through the unknown territory of conducting research and studying for a PhD. Their encouragement that I really could do it has been invaluable. I am also grateful to the members of my Research Advisory Group who helped me to understand local healthcare provision, and gave helpful feedback in the analytical stage of the study.

I am indebted to everyone who took time to participate in the study, both the health care professionals who made time in their busy schedules, and the patients who supported the work during what was a difficult time in their lives.

The support and encouragement from everyone in, who has passed through, or even who drops in for coffee in ‘Room 10’, cannot be measured. I have learnt so much from everyone, and they have been providers of both laughter and common sense advice about both life and the problems faced during my study. Particular thanks to Gretl McHugh, Jane Griffiths, Linda McGowan and Sue Kirk who all took the time to read drafts of the thesis for me.

The greatest thanks must go to my family. To my father, who proof-read the thesis, although I take responsibility for all stray apostrophes remaining! And to Kieran, Siobhan, Ruth, Michael and Daniel who have, with love and good humour, put up with my many absences as wife and mother over the last four years. Without their encouragement that this was a worthwhile venture, it would never have been completed.
The Author

This section briefly sets out my work and research experiences to date, with particular reference to both the interest in palliative care which led me to conduct the research presented here, and the research experiences I have had before and during this study.

Qualifications

1995-1996  University of Wales College of Medicine, Cardiff
Diploma in Palliative Nursing

Master of Science in Nursing (with distinction)

1983 - 1987  University of Manchester, Oxford Road, Manchester
Bachelor of Nursing (Honours) Class I. RGN, DN Cert.

Background

My background prior to commencing studying for this PhD was primarily working as a nurse in palliative care fields. Chronologically, my work experience initially involved working in hospital settings as a staff nurse in haematology and HIV/AIDS settings. I then moved to working in community settings as a district nurse, district nurse manager and more recently as a community Macmillan nurse. My post immediately prior to commencing this study was as a Macmillan palliative care services co-ordinator, working across a health authority area with responsibility for coordinating palliative care services across the hospital, community, social care and voluntary sectors, working with the emerging cancer networks, and working with others to develop local palliative care strategy, policy and protocols.

It was working in this post which developed my interest in referrals to and within community palliative care services. I had been aware of differences in referral patterns on a small scale whilst working with several teams of district nurses and general practitioners as a community Macmillan nurse. When working with many different professionals across a health authority area, the extent of the variability in referral practice, and the different approaches people had to workload and
caseload management became more apparent to me. This led directly to the formulation of the research question this study was designed to attempt to answer.

**Research experience**

Prior to the studies which formed part of this PhD, my only experience as a researcher was the research which I conducted in the final years of both my Bachelor’s and Master’s degrees. The small scale study which I conducted as an undergraduate investigated the attitudes of diabetics towards their illness and the education they had received to allow them to manage it. The research for my Master’s degree used a phenomenological approach to look at people’s lived experience of venous leg ulceration.

I would therefore consider myself a neophyte researcher. The educational opportunities afforded to me as part of my studies have therefore been invaluable in allowing me to develop some research expertise. I have completed assessed courses in qualitative and quantitative research methodology, survey and historical research methods, statistics, and collaboration in primary care as part of this degree. In addition, I have accessed other educational opportunities such as specific training in the software used like Nvivo™, and in the methodology chosen, attending a course on case based research methods.
Chapter one

Introduction to the study
1.1 Introduction

Community palliative care services appear central to the provision of high quality palliative care to patients and carers. It has been estimated that 80% of people needing palliative care spend most of their last year at home (Higginson, 1993), and that home is the preferred place of care and death (Higginson and Sen-Gupta, 2000). It is therefore probable that services providing care in home and community settings are critical to the way patients and their carers experience the palliative phase of illness.

Much research focuses on the outcomes and effectiveness of such care, particularly care given by those who specialise in palliative care provision. Reviews of the outcomes of specialist palliative care have found evidence of its effectiveness, particularly in the field of pain control, although the evidence is often equivocal (Hearn and Higginson, 1998; Smeenk et al., 1998; Salisbury et al., 1999; Wilkinson et al., 1999; Critchley et al., 1999; Goodwin et al., 2002b; Higginson et al., 2003). Recent research supports the supposition that palliative care at home is likely to have a positive impact on patients’ care and experience: that provision of formal care at home appears to increase the likelihood of home death (Klinkenberg et al., 2005); and that patients experience better pain control after referral to community palliative care services (Boström et al., 2004).

Appropriate and timely referral to services providing palliative care in the community is likely to be an important pre-cursor to providing the best care possible. However, these reviews focus on outcomes, revealing little about the antecedent structures and processes of care. They do not explore whether the most appropriate patients had been chosen to receive the services studied in a timely manner. In addition, most studies investigate the impact of specialist services, not reflecting the possibility that many will be well cared for outside such services. There is currently little understanding about how all those working to provide community palliative care make decisions about to whom and by whom palliative care should be provided, and whether such referrals meet the needs and expectations of patients.
The study presented in this thesis investigates referrals within community palliative care services. To put the study in context, definitions of palliative care are discussed, and policies that may affect the way palliative care is provided and referrals made are examined.

1.2 Defining palliative care and its provision

The World Health Organisation provides the most quoted definition of palliative care, which has been recently updated:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

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.

(Sepúlveda et al., 2002 p.94)

This definition highlights an increasing move away from the cure versus care model of palliative care implicit in past definitions, which relegated palliative care to the last stages of life. Now there is awareness that the palliative care principles presented in this definition should be applied as early as possible to the course of any ultimately fatal illness (Sepúlveda et al., 2002).

This definition infers that palliative care is a way of approaching patient care, not a particular service. The importance of teamwork in palliative care is emphasised,
but who could or should form part of such a team is not specified. There is therefore some ambiguity in the definition, not about what palliative care is, but about who could or should be providing such care.

Whilst such ambiguity may acknowledge differences in health care systems, as a result other authors offer further descriptions of the way services could be organised. A common division, which is reflected in the way many services are organised in the UK, is between those who specialise in providing palliative care, and those who are generalists, but whose care follows a palliative care approach. General community palliative care may be given by all health and social care professionals, and is likely to include care given by general practitioners, district nurses and allied health professionals such as physiotherapists, dieticians and occupational therapists. Specialist community palliative care is likely to include care given by doctors, nurses and allied health professionals whose main focus is palliative care, and other services delivering care in the home such as hospice at home, and possibly day care such as day hospice care (Tebbit, 1999).

This division between generalist and specialists is emphasised in guidance given to commissioners of palliative care (Tebbit, 1999), and felt to be a needed further element of the WHO definition of palliative care (Ahmedzai et al., 2004). Ahmedzai et al. (2004) argue that the definition of palliative care must be taken further, with concepts of basic and specialised palliative care added. They relate this explicitly to referral between services, arguing that if a patient has symptoms that cannot be controlled by their current general health care team, they have a right to be referred to a specialist team, and the current provider has an obligation to refer. That such a statement needs to be made implies that referrals between general and specialist providers may not always be made.

The apparent likelihood of a positive outcome for patients receiving palliative care services gives an added impetus to ensuring that those who require such services receive them. However, the concerns about rights and obligations regarding referrals imply that possibly those who require services may not be accessing them equitably. The concept of equitable access is therefore explored further.
1.3 **Equitable access to care**

There is evidence that the needs of patients are not always equitably met by palliative care services. Needs assessments in palliative care have traditionally taken an epidemiological approach (Higginson, 1997). Few attempts have been made to relate symptoms experienced by patients to their importance, debility caused or the type of care that might ameliorate them (Franks *et al.*, 2000). There is also evidence that patients who may require palliative care services are not accessing them equitably. Socio-economic and diagnosis related issues appear to affect utilisation considerably, with for example, those who are older, who do not have a cancer diagnosis, who are not married, and who experience some degree of poverty being less likely to be users of palliative care services (Grande *et al.*, 1998; Ahmed *et al.*, 2004).

Despite this evidence of practice to the contrary, there is a strong assumption of the importance of equitable access in literature and policy. Health has been described as a human right, and ensuring access to health care as key to achieving this goal (Gulzar, 1999). Equity is a form of equal access to health care for people in equal need (Goddard and Smith, 2001). This is a fundamental tenet of the National Health Service, that its health care should be available to all on the basis of clinical need (Mathew *et al.*, 2003). Equity is also explicitly an aim for palliative care, with a promise that ‘all patients should have access to specialist palliative care advice and services that they need’ in the NHS cancer plan (Department of Health, 2000a).

Access is the degree to which a system inhibits or facilitates the ability of an individual to gain entry and to receive services. Thus accessibility includes geographic, architectural, transportation, social, temporal and financial considerations. Access is also a function of the availability of health services and their acceptability (Gulzar, 1999). The World Health Organisation defines accessibility:

> accessibility implies the continuing and organised supply of care that is geographically, financially, culturally and functionally within easy reach of the whole community. The care has to be appropriate and adequate in content
This notion of accessibility focuses on the characteristics of the health care system, however models of access to health care also focus on the characteristics of potential users (Khan and Bhardwaj, 1994). Such a focus on potential users of health care services is found in the classic behavioural models of access to health care. Andersen’s (1995) model for example, focuses on the behaviour of the individual in seeking access to health care. Indeed, Khan and Bhardwaj (1994) note that research on access has concentrated on user characteristics, and has only recently started to look at health care system characteristics.

This certainly appears to be the case in access research in palliative care which has a strong focus on the way patient characteristics such as age and ethnicity affect access to services (Grande et al., 1998; Ahmed et al., 2004). Continued research into access to palliative care has been recently recommended, particularly further research to identify economic, geographic, and cultural disparities in access to palliative and end-of-life care (Hagen et al., 2006). Whilst this research may continue to be important, it might be that further research into the health care system characteristics which affect equitable access would also be important.

Examining notions of equality and access therefore highlights two potential research issues: the need to study how the health care system affects access as much as individual behaviours; and the need to relate access to some measure of need. The concepts of vertical and horizontal equity seem to underpin these issues. Horizontal equity is the equal treatment of equals, and vertical equity the unequal, but equitable, treatment of unequals (Mooney and Jan, 1997). Mooney and Jan (1997) suggest that most research assumes concerns for horizontal equity, that equal use of healthcare is equitable, rather than vertical equity which requires some judgement as to the need for healthcare, and its likely benefits.

Theories of equity and access also underpin contemporary palliative and health care policy, and the policy context within which this study takes place is now discussed.
1.4 The policy background to the study

This brief review of the policy context within which the study took place is structured around three broad concepts which appear to critically underpin recent policies influencing palliative care: equity of access, partnership, and community.

**Equity of access**

The concept of equity of access to health care is a central objective of many health care systems, and has been an important buttress of the National Health Service since 1948 (Goddard and Smith, 2001). A review of the development of palliative care in policy from 1986 – 2000 found that such concepts are also core to policy in this area (Mathew et al., 2003).

This concept of equity of access underpins the principles of a primary care led NHS suggested by ‘Primary care: delivering the future’ (Department of Health, 1996). It is argued in this policy document that the principles of a primary care led NHS are quality, fairness, accessibility, responsiveness and efficiency. Subsequent national health policy continues to emphasise equity and access. In ‘Building on the best. Choice, response and equity in the NHS ’ (Department of Health, 2003a p.6), it is stated that ‘modern public services should provide a high quality service meeting the individual needs of an increasingly diverse population whilst also being underpinned by the values of fairness and equity we all hold in common’. This policy document also contains a specific pledge regarding end of life care: ‘to offer all adult patients nearing the end of life, regardless of their diagnosis, the same access to high quality palliative care so that they can choose if they wish to die at home’ (p. 46). This aim was specifically investigated by the House of Commons Health Committee (2004). They noted the current lack of equity in palliative care provision by geographical area, by patient group, and by disease. The most recent health policies affecting palliative care focus around the End of Life Care programme (End of life care programme, 2006). This Department of Health initiative has a particular focus on equitable access, aiming to ‘improve the choice, equity and responsiveness for all adult patients nearing the end of life’, and particularly focuses on the spread of tools to support high quality care for end of life (End of life care programme, 2006).
Local health policies are also concerned with equity of access. One study of local health improvement plans found that palliative care was represented in many plans, with key issues identified as an awareness of inequalities of access and distribution of services (Seymour et al., 2002b).

The concept of equity of access to palliative care has also been internationally emphasised. The recent Korea declaration on hospice and palliative care (2nd Global Summit of National Hospice and Palliative Care Associations, 2005) agreed that access to hospice and palliative care should be a human right, and that hospice and palliative care must be provided according to the principles of equity, irrespective of age, race, gender, sexual preference, ethnicity, faith, social status, national origin and the ability to pay for services. This declaration both reiterates the importance of equity of access within palliative care services, and emphasises the potential influence of user characteristics on access.

The concept of equity of access underpins international, national and local policies influencing the provision of palliative care, with specific pledges made to offer palliative care equally to all in need.

**Partnership**

A second key theme apparent in current policies affecting palliative care provision is partnership. A focus on partnership working in palliative care is highlighted by the Calman-Hine report of 1995 which outlines the need for multi-professional specialist palliative care teams which should integrate in a seamless way with cancer treatment services to provide the best possible quality of care and life (Finlay, 2001). Such teamwork has been a continuing focus of palliative care, exemplified in the definition of palliative care above.

There have been moves to acknowledge partnership as a key principle guiding all care provision. ‘The new NHS, modern, dependable’ (Department of Health, 1997) identifies partnership as one of the six key principles to be enacted in the health act of 1999. This move towards partnership as a key way of delivering services is also emphasised in recent policy guidance on providing supportive and palliative
care services (NICE, 2004), and in specific guidance on end-of-life care in ‘Our health, our care, our say’ (Department of Health, 2006).

‘We will establish end-of-life care networks … these will improve service coordination and help identify all patients in need. The networks will bring together primary care services, social services, hospices and third-sector providers, community based palliative care services as well as hospital services.’ (Department of Health, 2006 p.103)

Partnership is therefore recommended as a key way in which palliative care, and thus access to palliative care should be delivered.

**Community**

The third issue apparent from current policy is the increasing drive to place the community as a key location of care. This is reflected in a series of policy documents, including the NHS plan (Department of Health, 2000b), primary care policy (Department of Health, 1996), and the cancer plan (Department of Health, 2004). This shift from a focus on hospital based care reflects the experience of many patients in the palliative phase of their illness, and may be the preferred location of care.

1.5 **Summary**

Equitable access to palliative care services in the community according to clinical need is a key concern. Some patients are less likely to access palliative care services than others. Given evidence that such care is of benefit, then this inequity of access may to lead to poorer outcomes for some.

What is much less clear is why this apparent inequity in access occurs. Whilst recent research into outcomes of care is laudable, without an understanding of the antecedent structures and processes it is difficult to make sense of outcomes, replicate outcomes between services or most importantly improve outcomes for patients. The way that referrals are made and received may be key processes underpinning equity of access. The literature about access within general and specialist community palliative care services is now reviewed to explore this area further, and identify areas which warrant further study.
Chapter two

Literature Review
Studies exploring factors affecting patients’ access to general or specialist community palliative care services are examined in this literature review. An initial examination of this literature revealed its heterogeneity, indicating that multiple different potential factors may facilitate or impede referral processes. This literature review is therefore a broad, but rigorous and methodical, examination of research investigating access to general or specialist community palliative care services. It is primarily a review of empirical literature, reflecting the search results. Theoretical literature which could assist in illuminating and interpreting the findings of the research is discussed in chapter 9.

2.1 Review strategy

The literature review was conducted in two phases, both with the same search and review strategy. The first literature search and review was conducted in early 2003 and the results from this review influenced the study questions, design and implementation. This search and review was formally updated in March 2006, and this review is reported here, incorporating literature published during the study as well as the results from the initial search.

2.1.1 Search strategy

The search strategy encompassed three main strands: the search of electronic databases, hand searching the indexes of relevant journals, and searching the reference lists of relevant studies and published reviews.

Electronic databases

Literature searches were carried out using the eight electronic databases that appeared most appropriate to the subject, and which had been used most frequently in other related literature reviews. The start and end points were the earliest and latest searchable dates for each database, to ensure as many relevant studies were captured as possible. There are few reviews of this literature, hence the desire not to artificially truncate the search by date. The databases were Ovid Medline (1966 – 2006), Cinahl (1982 – 2006), PsycINFO (1967 – 2006), SIGLE (1980 – 2003), ASSIA (1997 – 2006), CancerLit in Pubmed.
(1960 – 2006), Embase (1974 – 2006) and the Cochrane databases. Whilst the SIGLE database of grey literature was searched in the earlier review, this database was not available for the second search. However, there is evidence that grey literature searches are not particularly effective in finding palliative care studies (Cook et al., 2001), and there were no relevant studies found in the initial search.

Each search was constructed differently to use the relevant search terms or MESH/Thesaurus/Keyword headings for each database. All searches essentially combined all terms found (and their truncated forms) for the three foci of the search: palliative care; community care; and access (Table 2.1).

Table 2.1   Examples of terms used in the literature review search strategy

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<th>Terms for community care and</th>
<th>Terms for access and</th>
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<td>All combined with or</td>
<td>All combined with or</td>
<td>All combined with or</td>
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<tr>
<td>Palliative</td>
<td>Primary care</td>
<td>Access</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Primary health care</td>
<td>Access to care</td>
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<tr>
<td>Specialist palliative care</td>
<td>Community care</td>
<td>Referral</td>
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<tr>
<td>Terminal</td>
<td>Home care</td>
<td>Barriers</td>
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<tr>
<td>Terminal care</td>
<td>Home health nursing</td>
<td>Obstacles</td>
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<tr>
<td>Terminally ill</td>
<td>Community nursing staff</td>
<td>Decision making</td>
</tr>
<tr>
<td>End of life</td>
<td>General Practitioners</td>
<td>Equity of care</td>
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<tr>
<td>End of life care</td>
<td>Family Practice</td>
<td>Equality of care</td>
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<tr>
<td>Hospice</td>
<td>Family medicine</td>
<td>Inequity and inequality</td>
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<tr>
<td>Hospice care</td>
<td>Family Physicians</td>
<td>Rationing</td>
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<td></td>
<td>Home health aides</td>
<td>Gatekeeping</td>
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<td>Home care services</td>
<td>Evaluation of care</td>
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<td></td>
<td>Home visiting programs</td>
<td>Assessment of need</td>
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<td></td>
<td>Unmet need</td>
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<td></td>
<td></td>
<td>Health care need</td>
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<td></td>
<td></td>
<td>Health services needs and demands</td>
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<td></td>
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<td>Health care utilization</td>
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<td></td>
<td></td>
<td>Self referral</td>
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<td></td>
<td></td>
<td>Professional referral</td>
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<td></td>
<td></td>
<td>Health service accessibility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Delivery of health care</td>
</tr>
</tbody>
</table>

- 26 -
The latter search incorporated some additional term synonyms garnered from the search strategy of a recent review (Ahmed et al., 2004). An example of the search strategy adopted for one database is found in appendix 1.

This search strategy was quite non-specific, with, for example, over 3,000 hits on the Ovid Medline search, which resulted in 192 abstracts being further scrutinised, and 113 papers obtained for full review. It proved difficult to amend the search without affecting recall or precision, an acknowledged issue in electronic searching (Shaw et al., 2004), and so the original strategy remained. All studies were reviewed in full if they investigated any aspect of access in community palliative care for adults.

**Additional search strategies**

In addition to searching electronic databases, bibliographies of review articles and the studies obtained were scrutinised, as using electronic databases alone has been demonstrated to not identify all relevant studies, particularly in fields where there is complex evidence and where clinical trials do not predominate (Crumley et al., 2005; Greenhalgh and Peacock, 2005). In addition, the tables of contents of the journals ‘Palliative Medicine’ (1997 onwards) the ‘Journal of Pain and Symptom Management’ (1988 onwards), ‘International Journal of Palliative Nursing’ (1996 onwards) and ‘Progress in Palliative Care’ (2003 onwards) were hand searched. These journals were chosen as they are locally electronically available from these dates and commonly report palliative care studies. For the duration of the study (2002 – 2006) electronic tables of contents were also obtained via ZETOC alert for scrutiny from the journals listed in appendix 2. These represented the journals which appeared from the initial searches to be most likely to report relevant studies, and this strategy meant that relevant papers were identified immediately, and could influence the conduct of the study.

### 2.2 Critically appraising the studies reviewed

There is no definitive approach to critical appraisal of studies in reviews which integrate the findings of studies using a variety of methodological approaches. Systematic reviews often grade evidence in a hierarchical way, highlighting the
pre-eminence of randomised controlled trial methodology, and then appraising methodological rigour of the studies included according to criteria designed to appraise such trials (Moher et al., 1995; Khan et al., 2001), and there are examples of this approach in the palliative care literature (e.g. Higginson et al., 2003). However, in conjunction with a growing literature highlighting alternative review strategies, there is a commensurate realisation that such appraisal criteria may not be suited to some reviews, or to particular elements of a review, or even required at all (e.g. Khan et al., 2001; Whitemore and Knafl, 2005; Pawson et al., 2005; Mays et al., 2005; Dixon-Woods et al., 2005; Pawson, 2006). Much of this discussion stems from the ongoing philosophical, methodological, and practical debate about how to appraise the quality of qualitative research such that no definitive, accepted criteria have thus far been accepted despite the publication of different approaches (Sandelowski, 1993; Popay et al., 1998; Cutcliffe and McKenna, 1999; Lincoln and Guba, 2002; Morse et al., 2002; Spencer et al., 2003; Boaz and Ashby, 2003).

This essentially narrative review aimed to critically appraise studies in a way which has utility for understanding how the conduct of the research impacts on the findings, their implications for practice, and their interpretation by others. This is essentially a ‘fitness for purpose’ argument (Boaz and Ashby, 2003; Pawson et al., 2005) in addition to a core appraisal of methodological rigor. Boaz and Ashby (2003) summarise this by asking four questions of research reports: quality and transparency in reporting (is the research presented in such a way that can be appraised and used by others?); methodological quality (was the research technically well executed?); appropriateness of the methods (does the research approach match the defined purpose of the study); and quality of the messages in the research (does the research address important policy and practice questions in a way that is both useful and useable)? These are the key questions which guide the reporting of the strengths and limitations of the research reviewed.

A review score is also given to aid an overall judgement of the quality of the research. The review score used was developed by Hawker et al. (2002) in response to the lack of criteria suitable to appraise studies from different methodological backgrounds. It is used here both because the appraisal domains map onto the questions above, and because it was used in the most recent
published review into access in palliative care (Ahmed et al., 2004). The review score examines nine study domains: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalisability and implications and usefulness. Each domain can be scored from 1 (very poor) to 4 (good), such that a study can score between 9 and 36 points. The review scoring system is found in appendix 3.

2.3 The structure of the literature review

The search of the literature identified a broad range of studies into different aspects of access within general and specialist community palliative care services. They are presented here thematically to answer the following questions which typically guided studies:

- When are patients referred to community palliative care services?
- How many patients are referred to community palliative care services?
- Which patients are referred to community palliative care services?
- What reasons are given for referral to community palliative care services?
- Who refers patients?
- What are patients’ and carers’ views on referral to community palliative care services?
- What factors act as barriers to or facilitate referrals from professionals to community palliative care services?

2.3.1 When are patients referred to community palliative care services?

Studies are reviewed which either investigate the timing of referrals to community palliative care services as a core research question, or report some data relating to timing in a related study. The studies reviewed are summarised in table 2.2. As with all of the summary tables, an individual critique of the study in conjunction with the review score is found in this table. The narrative review focuses on presenting a thematic overview of studies and general critique of the study area.
The most commonly reported information related to timing of referral to community palliative care services is the length of time a patient received a service before they died. Studies investigating the average (usually median) time from referral to the service to death have found that many patients die within one or two months of referral to a service. Table 2.3 summarises this information from the studies reporting this data.

Table 2.3  Time from referral to death for patients referred to different palliative care services

<table>
<thead>
<tr>
<th>Study</th>
<th>Service studied</th>
<th>Time from referral to service to death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connor et al. (2004)</td>
<td>Hospice</td>
<td>20 days</td>
</tr>
<tr>
<td>Good et al. (2004)</td>
<td>Home palliative care</td>
<td>54 days</td>
</tr>
<tr>
<td>Costantini et al. (2003)</td>
<td>Palliative home care team</td>
<td>49 days</td>
</tr>
<tr>
<td>McCarthy et al. (2003a)</td>
<td>Hospice</td>
<td>25 days - lung 28 days - colorectal</td>
</tr>
<tr>
<td>Miller et al. (2003)</td>
<td>Hospice home care</td>
<td>43% referred in last week of life</td>
</tr>
<tr>
<td>Stuart et al. (2003)</td>
<td>Early ‘transition’ care programme</td>
<td>260 days</td>
</tr>
<tr>
<td>Grande et al. (2002)</td>
<td>Hospital at home scheme</td>
<td>10 days</td>
</tr>
<tr>
<td>Lamont and Christakis (2002)</td>
<td>Outpatient hospice</td>
<td>26 days</td>
</tr>
<tr>
<td>Virnig et al. (2002)</td>
<td>Hospice</td>
<td>23 days</td>
</tr>
<tr>
<td>Casarett (2001)</td>
<td>Hospice</td>
<td>13 days</td>
</tr>
<tr>
<td>Casarett and Abrahm (2001)</td>
<td>‘Bridge’ programme</td>
<td>52 days</td>
</tr>
<tr>
<td>Christakis and Iwashyna (2000)</td>
<td>Hospice</td>
<td>30 days</td>
</tr>
<tr>
<td>Costantini et al. (1999)</td>
<td>Hospice</td>
<td>38 days</td>
</tr>
<tr>
<td>Stillman and Sryjala (1999)</td>
<td>Hospice</td>
<td>23 days</td>
</tr>
<tr>
<td>Bennett and Corcoran (1994)</td>
<td>Home and hospital specialcare</td>
<td>26 days (1989) 29 days (1992)</td>
</tr>
<tr>
<td>Christakis (1994)</td>
<td>Hospice</td>
<td>29 days</td>
</tr>
<tr>
<td>Dunphy and Amesbury (1990)</td>
<td>Home hospice care</td>
<td>40 days</td>
</tr>
<tr>
<td>Komesaroff et al. (1989)</td>
<td>Home hospice care</td>
<td>6 weeks</td>
</tr>
<tr>
<td>Gray et al. (1987)</td>
<td>Home hospice</td>
<td>39 days</td>
</tr>
<tr>
<td>McCusker and Stoddard (1987)</td>
<td>Home hospice</td>
<td>2 months</td>
</tr>
<tr>
<td>Evans and McCarthy (1984)</td>
<td>Terminal care support team</td>
<td>49 days</td>
</tr>
</tbody>
</table>

There is evidence that the length of time patients spend within palliative care services may be decreasing, as a national US study found that whilst only 23% of patients in 1991-2 were in hospice for between 0 – 7 days rather than a longer period of time, by 1999-2000 this had steadily increased to 37%, a statistically significant difference (Han et al., 2006).
Some care should be taken interpreting these figures, as the spread of studies across different countries means that the services studied are often very different in their conception and operationalisation. For example, whilst ‘hospice’ in the UK is likely to refer to an in-patient hospice building and its associated services, in the US it often means a home hospice team providing intermittent care in similar ways to both a UK district nursing and hospice at home service. The difference in patterns of service provision of different countries is critical to interpretation of many of the studies reviewed here, and is considered throughout this review. In addition, little information is given about how the ‘routine’ data on length of stay is collected, and so its accuracy is hard to assess. However, what is clear from the commentary for most of these particular studies is that lengths of ‘stay’ within a community palliative care service are considered short, perhaps too short to fully meet the objectives of the service or the needs of the patient and their family.

Whilst data suggest that the timing of referral may be an issue, with only a short period of time between referral and death for many patients, studies which investigate the opinions of professionals, patients or carers towards such referrals confirm that the timing of referral is frequently perceived to be too late to be of full value. Recently Schockett et al. (2005) studied the views of family members about referral timing to two US home hospice services. Whilst reassuringly 83% of respondents felt that referral had come at the right time, 14% still felt that referral was too late. This finding correlates with length of stay, with ‘too late’ referrals having an average hospice stay of 21 days versus 31 for those referred at the ‘right’ time, with significant unmet needs identified for these patients. These perceptions are also found in the UK, with a recent study of patients and professionals identifying timeliness of referrals to specialist palliative care services as a main theme, with an awareness that some patients are referred too late to fully benefit from care (Bestall et al., 2004).

It is evident that these patients are often extremely ill at referral, with studies reporting that a large proportion of those referred have advanced disease, or metastatic cancer (Skilbeck et al., 2002; Potter et al., 2003). Whilst prognostication is known to be an inexact science (Vigano et al., 2000; Glare et al., 2003), it does appear from studies comparing referred and non referred patients to services that
those who have a longer period of time from diagnosis to death have a better chance of being referred to a palliative care service. For example, Costantini et al. (2003) found that the median time between first diagnosis and death was significantly longer for palliative home care team users (381 days) than non users (142 days). Lamont and Christakis (2002) also discovered that longer survival within the outpatient hospice service studied was associated with longer time since diagnosis at referral. Other studies also confirm that those referred to specialist palliative home care teams appear to have longer diagnosis to death times than those not referred (Gray et al., 1987; McCusker and Stoddard, 1987; Hunt and McCaul, 1996; Gray and Forster, 1997; Hunt and McCaul, 1998; Grande et al., 2002; Hunt et al., 2002). It is assumed that the longer time period may give more opportunities for referral, however the fact that referral to such services may prolong life cannot be entirely discounted. No studies were found which investigated the reasons for this disparity. It appears that patients who live longer with a disease are more likely to be referred, but the referral is made at a late stage in their illness.

There is also evidence to suggest that patients are referred to home based palliative care teams earlier than hospital or hospice based teams, where the median survival is often around 20 days from referral (Costantini et al., 1999, Dunphy and Amesbury, 1990, Komesaroff et al., 1989).

Given these widespread concerns about timing of referrals to specialist palliative care services, some studies investigate referral practices further. Such studies often find that professionals admit to referring patients late in the disease process (McKenna et al., 1999; Fellowes et al., 2003). Differences between professionals are also identified. Lowden (1998) found that whilst 26% of district nurses prefer to involve specialist palliative care services early, 48% of hospital nurses preferred early involvement. In contrast, fewer doctors favour early referral to palliative care, with 20% of hospital doctors favouring early referral, but only 9% of general practitioners. This finding is echoed by Bennett and Corcoran (1994) who found that the establishment of a hospital palliative care team increases the referral to death interval for home care patients, because they were being referred earlier by hospital based staff. It appears that professional issues have a significant impact on referral timing, as Lamont and Christakis (2002) found, when they discovered
that the frequency with which people refer, their skill in determining prognosis and their practice speciality all affected the timing of referral to specialist palliative care.

Whilst there is real strength in much of this literature in consistently identifying issues concerning late referral of patients, and recognising some issues with professional referrals to such services, there are also limitations to many of the studies. First, the research primarily investigates referrals to specialist community palliative care services, mainly home visiting services such as Macmillan nursing services, Marie Curie services or ‘home hospice’. The timing of the involvement of generalists such as district nurses or general practitioners in care is rarely explored. Given that, certainly in the UK, such specialist services almost inevitably provide care in conjunction with general services, such an omission in most of the studies makes the impact of late referral to specialist services hard to assess.

Second, there is a preponderance of retrospective studies, often using routinely collected data (21 retrospective studies vs. 5 prospective studies in table 2.2). It is difficult to assess the accuracy of the data used, and is of limited utility in understanding why referrals were made at a particular point in time.

Third, the timing of referral is generally expressed in terms of prognosis, particularly time from referral to death whilst receiving the service, or overall diagnosis to death times in relation to the likelihood of referral to services. What such research does not do is give an estimation of an appropriate timing of referral in relation to patient need. Some assumption that the timing is not correct in terms of needs can be made from research relating timing of referral to unmet need (Schockett et al., 2005), but most of the research fails to make such links. Given that much work needs to be done to make prognosis a more accurate predictor of when referral could be made, it seems likely that assessment of need could be a valuable predictor of referral timing, and should be addressed in future studies.
### Table 2.2  Studies investigating when patients are referred to community palliative care services

<table>
<thead>
<tr>
<th>Author, Date, Country</th>
<th>Research question/theme</th>
<th>Research approach</th>
<th>Participants</th>
<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Han et al. (2006) US</td>
<td>To examine trends in hospice usage</td>
<td>Retrospective analysis of data from National Home and Hospice Care Survey, National Nursing Home Survey, and Underlying and Multiple cause of death files</td>
<td>9 418 hospice patients</td>
<td>Length of service (0-7 days) increased from 23% (1991-92) to 37% (1999 – 2000), statistically significant</td>
<td>26 Useful insight into changing patterns of service use/patterns over a decade in US hospices</td>
</tr>
<tr>
<td>Schockett et al. (2005) US</td>
<td>1) Family members assessment of timing of referral to home hospice 2) Family members assessment of reasons for late referral to home hospice</td>
<td>Survey (telephone or mail)</td>
<td>237 of 416 (64% response telephone, 50% mail) family members of home hospice patients from two services who had died in the last 3 -6 months</td>
<td>2.5% perceived ‘too early’ referral, 83% right time, 14% too late. ‘Too late’ referrals had an average hospice stay of 21 days vs. 31 for ‘right time’, with statistically significant unmet needs</td>
<td>25 Method limitations: a proxy view, possible non response bias due to pre-selection of sample, small sample size Useful insight into how timing of referral affects perceptions of care</td>
</tr>
<tr>
<td>Bestall et al. (2004) UK</td>
<td>To assess current views of access and referral to specialist palliative care</td>
<td>Qualitative semi-structured interviews to explore the views of patients and professionals</td>
<td>12 health and social care professionals, 3 GPs, 6 community nurses and 13 patients. Identified in</td>
<td>Timeliness of referrals identified as a main theme: awareness that some patients referred to late to fully</td>
<td>24 Superficial description of timeliness data</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>Connor et al. (2004) US</td>
<td>To understand demographics, practices and outcomes of hospice care by developing a national database</td>
<td>Annual survey of hospice providers</td>
<td>All hospice providers in the US invited to submit data – response of nearly 900 hospices in 2002</td>
<td>Median length of service 20 days in 2002</td>
<td>24 Large dataset, but little comparison with needs or other norms</td>
</tr>
<tr>
<td>Lackan et al. (2004b) US</td>
<td>To examine whether variability in hospice use determined by patient characteristics has changed over time</td>
<td>Retrospective cohort design using routine data from linked Surveillance, Epidemiology and End Results – Medicare database to study hospice use</td>
<td>170,136 people identified who were 67+, diagnosed between 1991-96, and who died between 1991 – 1999, with breast, colorectal, lung or prostate cancer</td>
<td>Median length of stay virtually unchanged from 17 days in 1991 to 20 days in 1999. Mean stay increased from 28 days to 54 days</td>
<td>27 Useful large study, which indicates that variability in use may be decreasing with the expansion of services over time.</td>
</tr>
<tr>
<td>Good et al. (2004) Australia</td>
<td>1) Survival of patients after referral to palliative care (incl. home care) 2) compare to previous study 3) compare time in care program to diagnosis to death time</td>
<td>Retrospective study of routinely collected patient data from one hospice service</td>
<td>1138 patients admitted to service over period (1998 – 2000)</td>
<td>Median post enrolment survival was 54 days. 9.3% died within 7 days, 17% survived 6 months+. Large variation attributable to diagnosis. 17% of time from diagnosis to death spent in program</td>
<td>23 Date of diagnosis frequently unknown. Only looks at one service, which may have particular unexplored contextual reasons for results. No data on need</td>
</tr>
<tr>
<td>Costantini et al.</td>
<td>To determine the effect of a palliative</td>
<td>Quasi-experimental design using</td>
<td>189 PHCT patients matched to 378</td>
<td>Cases received PHCT care for a median of</td>
<td>29 PHCT functions not</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>(2003) Italy</td>
<td>home care team on hospital utilisation in the 6 months before death</td>
<td>retrospective data from existing records for PHCT users and matched cancer controls</td>
<td>controls in one area of Italy in 1991</td>
<td>49 days. Median time between first diagnosis and death significantly longer for PHCT users 381 days vs. 142 days</td>
<td>well described. Reports data a decade old. No power calculation</td>
</tr>
<tr>
<td>McCarthy et al. (2003a) US</td>
<td>To identify factors associated with hospice enrolment and length of stay in hospice in patients dying with lung or colorectal cancer</td>
<td>Retrospective analysis of routine data on Medicare beneficiaries diagnosed with lung or colorectal cancer and who died in 1998</td>
<td>62,117 lung cancer and 57,260 colorectal cancer patients.</td>
<td>Median length of stay for hospice patients was 25 days (lung cancer) 28 days (colorectal cancer). 20% of patients entered hospice within 1 week of death</td>
<td>26 No information known about hospice type or availability in this national study.</td>
</tr>
<tr>
<td>Miller et al. (2003) US</td>
<td>Whether timing of hospice referral is associated with continuous hospice home care</td>
<td>Retrospective study of routinely collected patient data from 21 hospice programs (same provider organisation)</td>
<td>28,747 service using patients who died between 1998 – 1999</td>
<td>43% received hospice home care only in last week of life. With increasing lengths of stay % using continuous care increases.</td>
<td>30 Useful, large, comparison across many different sites country wide. No data on need</td>
</tr>
<tr>
<td>Potter et al. (2003) UK</td>
<td>To describe patients referred to different components of palliative care services (inpatient hospice, inpatient hospital,</td>
<td>Retrospective case note review of 400 consecutive referrals to three palliative care centres.</td>
<td>400 patients whose case notes were reviewed</td>
<td>71% of patients with cancer had advanced disease on referral.</td>
<td>23 The accuracy and comparability of the note taking between the teams participating was not assessed</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>Stuart et al. (2003) US</td>
<td>To describe the clinical model of a home based care management program and its evaluation</td>
<td>Case control study together with after death surrogate survey</td>
<td>208 patients enrolled in the program where death would be 'unsurprising' within 2 years</td>
<td>Median length of stay in the program was 260 days. Patients who died on the program had a shorter mean length of stay.</td>
<td>24 An interesting evaluation of a non-hospice programme to promote early access to end of care</td>
</tr>
<tr>
<td>Fellowes et al. (2003) UK</td>
<td>Perceptions of district nurses towards referrals to Marie Curie Nursing Service</td>
<td>Questionnaire, based on conditions / prognosis of patient prompting referral.</td>
<td>879 district nurses of 1379 (64% response)</td>
<td>7% often consider referral at diagnosis, 48% when palliative care needed, 88% when terminal care needed and 95% when end-stage care needed</td>
<td>21 Difficult to appraise utility of study with no definition of 'incurable', palliative or terminal given – or apparently indicated to respondents</td>
</tr>
<tr>
<td>Grande et al. (2002) UK</td>
<td>To investigate the variables associated with referral to hospital at home for palliative care</td>
<td>Retrospective analysis of cancer deaths 1994-1995 of patients referred to service compared to random sample of cancer deaths from routine records</td>
<td>121 deceased cancer Hospital at Home (HAH) patients and 206 cancer registry patients</td>
<td>Referral to HAH occurred a median of 10 days before death, and 76% of patients died within 30 days of referral. HAH patients received later district nursing care</td>
<td>29 One of the few studies to track general as well as specialist service use. Some of the numbers using particular services are small</td>
</tr>
<tr>
<td>Hunt et al. (2002) Australia</td>
<td>To examine the uptake of designated palliative care services</td>
<td>Retrospective review of cancer deaths in 1999 using routinely collected data</td>
<td>3086 deceased cancer patients (2105 palliative care service users, 981 non users)</td>
<td>Lower usage of palliative care services with those surviving three months or less</td>
<td>24 No disaggregation of patients by type of palliative care service accessed</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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</tr>
<tr>
<td>Lamont and Christakis (2002) US</td>
<td>To evaluate the possible role of physician factors in survival of cancer patients receiving hospice palliative care</td>
<td>Prospective cohort study of all patients admitted to 5 outpatient hospices using routine patient data and telephone survey of referring physician</td>
<td>326 patients (76% completion rate) referred over 130 days in 1996</td>
<td>Median survival after hospice enrolment 26 days. Longer survival associated with patient factors (unmarried, time since diagnosis) and physician factors (speciality, accurate survival prediction)</td>
<td>25 Interesting data because it introduces the notion of physician factors in timing of referral. No information on type of service given. Arbitrary definition of accurate survival prediction</td>
</tr>
<tr>
<td>Skilbeck et al. (2002) UK</td>
<td>To describe the work of Macmillan nurse teams in the UK</td>
<td>Comparative case studies of 12 Macmillan nurse teams using a range of data collection methods including interviews, epidemiological data, case note reviews etc.</td>
<td>Prospective data on new referrals (814) to 12 teams of Macmillan Nurses</td>
<td>13% of patients referred died within 1 week of referral, 40% within 6 weeks, however, 1/3 were still alive at end of 8 week period. More patients referred at diagnosis to hospital specialist palliative care than home specialist palliative care. 65% of patients had metastatic disease</td>
<td>27 Comprehensive analysis of the workload and work patterns of a number of Macmillan nursing teams</td>
</tr>
<tr>
<td>Virnig et al. (2002)</td>
<td>To examine whether rates of hospice use differ according to patient characteristics</td>
<td>Retrospective analysis of routine data on cancer deaths in the District of Columbia</td>
<td>Records relating to 169 759 hospice deaths and 388 511 cancer deaths</td>
<td>Median length of stay for any cancer diagnosis was 23 days</td>
<td>23 No contextual discussion of what as meant by ‘hospice’</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>Casarett (2001) US</td>
<td>To determine whether differences exist between patients referred to hospice (inpatient and homecare) from academic or non academic centres</td>
<td>Retrospective cohort study using routine data</td>
<td>All 1691 patients admitted to the hospice between 1997 – 1999 who had then died or been discharged. 411 had been referred from an academic centre</td>
<td>Median length of stay of 13 days.</td>
<td>26 No disaggregation of homecare or in-patient care data.</td>
</tr>
<tr>
<td>Casarett and Abrahm (2001) US</td>
<td>To compare patients enrolled in a bridge program with those enrolled in hospice</td>
<td>Retrospective study of all patients admitted to the programs between 1997 – 1999 from routinely collected data</td>
<td>284 patients enrolled in the bridge program and 1 000 enrolled in hospice</td>
<td>Median survival for bridge patients was 52 days, and 20 days for hospice patients</td>
<td>26 Program described does not appear to be replicated in the literature elsewhere so transferability unclear</td>
</tr>
<tr>
<td>Christakis and Iwashyna (2000) US</td>
<td>To identify individual and market factors associated with the timing of hospice use</td>
<td>Retrospective review of routinely collected Medicare, census and area data</td>
<td>151 410 Medicare funded hospice enrollees admitted to all hospices in 1993 and followed up until 1999</td>
<td>Median survival after hospice enrolment 30 days. Earlier enrolment associated with being non white, female, older and with substance abuse, psychiatric disease or dementia</td>
<td>27 No disaggregation of data on in-patient and home hospice care. Analysis only on elderly Medicare patients, but is very large cohort and covers 80% of hospice population. No data on need</td>
</tr>
<tr>
<td>Costantini et al.</td>
<td>To develop a staging system for terminal</td>
<td>Multicentre (58) prospective study of a 601 patients of 3901 registered patients</td>
<td>Median survival after hospice enrolment 38</td>
<td>27 Appropriate method,</td>
<td></td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
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<tr>
<td>(1999) Italy</td>
<td>Cancer patients, validated against survival</td>
<td>Random sample of admissions to palliative care units (Mostly home or mixed hosp/home units)</td>
<td>(22%) referred over 6 months in 1995.</td>
<td>Days. 14% died within 7 days, 27% and 15% lived longer than 90 and 180 days. Significant association between survival and gender, cancer type, setting of first visit and type of unit</td>
<td>Although extending recruitment period may have resulted in better data. No data on need</td>
</tr>
<tr>
<td>McKenna et al. (1999) UK</td>
<td>To examine the perceptions of district nurses and GPs towards home hospice nurses</td>
<td>Postal questionnaires to district nurses and GPs</td>
<td>305 GPs (47% response) and 101 nurses (51% response)</td>
<td>70% of GPs (and 77% DNs) refer in last months, 41% (31%) in last weeks, 12% (10%) in last days and 7% (5%) in last 48hrs</td>
<td>22 Description of study poor, and identification of responders and non-responder differences absent. Focused again on prognosis timing, not need</td>
</tr>
<tr>
<td>Stillman and Syrjala (1999) US</td>
<td>To assess factors associated with timing of referral to hospice</td>
<td>Retrospective review of routine medical records of patients dying in one hospice in 4 months in 1995/6</td>
<td>101 patients of deceased patients whose caregivers answered a satisfaction survey</td>
<td>Median length of stay 23 days. 32% died within 2 weeks, 13% within 1 week of admission. Caregivers more satisfied if length of stay &gt;30 days</td>
<td>24</td>
</tr>
<tr>
<td>Hunt and McCaul (1998) Australia</td>
<td>To determine changes in proportion, types and usage patterns of hospice users over time</td>
<td>Retrospective analysis of hospice and population cancer deaths using routinely collected data in 1990</td>
<td>2800 patients in 1990 (1239 hospice, 1561 non hospice), 2873 in 1993 (1060 hospice, 1813 non hospice)</td>
<td>Those with a longer survival time were more likely to use hospice</td>
<td>24 No disaggregation of data from different hospice types</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<td>Research approach</td>
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<tr>
<td>Lowden (1998) UK</td>
<td>Examines perceptions of health care professionals on when and how the decision to refer the patient to palliative care services is made</td>
<td>Questionnaires to hospital and community based staff</td>
<td>Randomly selected GPs (21), community nurses (19) and hospital nurses (22) and doctors (18) within one health district. 67% response rate</td>
<td>Nurses more favourable of early referrals than doctors, and hospital staff more favourable than community staff. 26% hosp nurses, 48% comm. Nurses, 20% hosp docs, 9% GPs</td>
<td>22 Description of conduct of study poor, and identification of type of service referred to non specific, but findings of interest in identifying differing attitudes towards referral timing</td>
</tr>
<tr>
<td>Gray and Forster (1997) UK</td>
<td>To identify and compare those who received specialist palliative care and those who did not</td>
<td>Retrospective study of deceased cancer patients identified from death register, cross referenced with data from palliative care services records</td>
<td>521 patients who died in 1991 (157 received SPC, 354 did not)</td>
<td>Median survival from diagnosis for those receiving specialist palliative care was 242 days, for those not receiving care was 110 days – reached significance</td>
<td>24 No disaggregation of data from different specialist palliative care services – including home care as well as other services</td>
</tr>
<tr>
<td>Hunt and McCaul (1996) Australia</td>
<td>To determine the coverage of hospice care in South Australia, compare service and non-service users and evaluate the impact of hospice on place of death</td>
<td>Retrospective study based on record review and routinely collected data of all deceased cancer patients</td>
<td>2 800 deceased patients in South Australia in 1990, of whom 1561 had hospice involvement</td>
<td>Those who survived more than six months following diagnosis were more likely to be involved with a hospice</td>
<td>24 No disaggregation of data from different specialist palliative care services – includes home care as well as other services</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<tr>
<td>Christakis (1994) US</td>
<td>To identify predictors of timing of patient referral</td>
<td>Retrospective cohort analysis of routinely available patient data</td>
<td>405 hospice outpatients</td>
<td>Median survival time at the hospice was 29 days, 15% died within 7 days, and 12% lived longer than 180 days. Oriented, depressed, prostate patients and cardiovascular patients had lower death rates</td>
<td>25 Data attributable to one service, but no relationship made between need of patients with different characteristics and the timing of their referrals</td>
</tr>
<tr>
<td>Dunphy and Amesbury (1990) UK</td>
<td>To identify characteristics which may distinguish between home care and inpatient hospice patients</td>
<td>Retrospective review of patients using routinely collected data</td>
<td>404 in-patient hospice patients and 143 home care patients who either died or were discharged from one hospice in 6 months in 1988.</td>
<td>Significant difference in average time from initial involvement to death was 22 days for in patient hospice group and 40 days for home care group.</td>
<td>23 Little description of data analysis procedures</td>
</tr>
<tr>
<td>Komesaroff et al. (1989) Australia</td>
<td>To study patients admitted to the inpatient and homecare component of a hospice programme</td>
<td>Prospective analysis of patients admitted to either programme over 12 months between 1985 – 1986</td>
<td>243 patients (108 in-patient, 135 home care)</td>
<td>Median survival 2.6 weeks for in-patient group and 6.0 weeks for home care patients</td>
<td>23 One of the first studies to identify the differences between home care and in patient patients at referral. Allocation to programmes made by the hospice, not referrer, and this bias not addressed</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<td>Research approach</td>
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<tr>
<td>Gray et al. (1987) Australia</td>
<td>To compare the costs of a home hospice palliative care service with conventional terminal care</td>
<td>Retrospective analysis of routine data</td>
<td>98 deceased patients from the home service (1983) and 98 deceased matched controls</td>
<td>Mean period of time spent under HPCS was 38.8 days</td>
<td>22 Only looked at last 90 days. Assumption made that controls would be matched in terms of symptoms which may be false.</td>
</tr>
<tr>
<td>McCusker and Stoddard (1987) US</td>
<td>To evaluate a home palliative care programme</td>
<td>Quasi – experimental time series evaluation using routine death and service use data collected before during and after implementation of home palliative care service</td>
<td>1874 deceased under 65 year old residents of one area – cancer deaths – 1976 - 1982.</td>
<td>Average time between first admission to home care and death for service users was 2 months. Home care users significantly more likely to have been diagnosed for a longer period before death</td>
<td>26 Users who died within one month of diagnosis excluded, and only claims within last 6 months of life included. Only studied under 65 y.o.</td>
</tr>
<tr>
<td>Mor et al. (1985) US</td>
<td>To compare characteristics of patients admitted to hospital based hospice with those admitted to home based hospice</td>
<td>Prospective data collection from routine records of admissions to home or hospital based hospice where a choice existed between the two</td>
<td>5912 patients (3446 hospital, 2466 home) in 17 (9 hospital, 8 home) hospices in 10 distinct geographical areas</td>
<td>Significantly shorter length of stay in hospital based hospice</td>
<td>23 Timing of referral/length of stay data not fully discussed. 30 mile radius for choices appears larger than would be practicable</td>
</tr>
<tr>
<td>Evans and McCarthy (1984) UK</td>
<td>Information about the workings of a terminal care support team (home and hospital)</td>
<td>Retrospective record review of referred patients compared to death certification records</td>
<td>125 referred patients who lived within the district compared to 437 cancer deaths overall</td>
<td>Median survival after first contact with the team was 49 days.</td>
<td>21</td>
</tr>
</tbody>
</table>
2.3.2 How many patients are referred to community palliative care services?

Palliative care services in the community, particularly specialist palliative care services, are rarely accessed by every patient who may be expected to benefit from such intervention. Many studies therefore estimate the reach or utilisation of services by tracking service use over time or at a particular point and comparing this to an estimation of the population who could benefit from or been eligible for such services. Studies which report data illustrating the utilisation of community palliative care services are discussed here, and summarised in table 2.4.

Studies which track the uptake of services over time frequently find an increase in the use of community palliative care services. For example, Fassbender et al. (2005) analysed the use of hospice services by patients dying of cancer each year between 1993 and 2000 in one Canadian region. They found that palliative homecare use increased from 44% to 57%, although the most increase took place at the start of the study period when there were changes to homecare provision. Similar trends have been identified in the use of other Canadian palliative care programmes, with an increase from 39% in 1992 to 62% in 1997 (Burge et al., 2002). Comparable increases have been found in Australia, from 53% of patients using hospice services in 1990 to 63% in 1993 (Hunt and McCaul, 1998), Italy, from 1.6% of patients using a palliative home care service in 1986 to 8.0% in 1990 (Costantini et al., 1993) and the US, from 11.5% of breast cancer patients who died in 1991 to 27.1% in 1996 (Lackan et al., 2003).

Two older studies found little change in the use of services over time. Cartwright (1991a) found that the proportion of patients who died and used district nursing services was constant at around 30% in both 1969 and 1987, and McCusker and Stoddard (1987) report that 46% of patients used a home palliative care service over 1976 – 1982, with few changes between years.

Most studies estimate the proportion of people using palliative care services at a moment in time, rather than trends in referral. Whilst mainly focused on the use of services by those with cancer, an increasing number of studies recognise the potential palliative needs of all patients nearing the end of life, and more recent
studies report use by all those dying in a particular area, or those dying from conditions other than cancer. Studies reporting palliative care use by all those who died, irrespective of cause, include studies in long term care facilities which found that 22% of residents accessed hospice services (Munn et al., 2006); a randomised controlled trial of an intervention in nursing homes which increased hospice use to 20% of those who died rather than 1% (Casarett et al., 2005); a study of those who died at home or in care which found that 12% had home nursing services and 51% home hospice services (Teno et al., 2004); a study of elderly people dying out of hospital found that 62% were enrolled in hospice care (Tilden et al., 2004); and a study of those dying from many different diseases which found that 34% were enrolled in a hospice (Hanson et al., 1999).

All these studies were conducted in the US, where home hospice services are organised and funded in very different ways to services in the UK, and which provide much care akin to that which district nurses provide in this country, as well as more specialised elements of care, often funded by Medicare. It is unlikely that similar studies in the UK would find such proportions accessing specialist palliative care services, as generally only about 5 – 10% of referrals are patients without malignant conditions (Skilbeck et al., 2002). This is indicated in a small study in one practice which found that 28.4% of patients who died had involvement of the practice’s general nursing staff (Lakasing and Mahaffey, 2005). Whilst the involvement of specialist staff was not examined, it is likely that it would be a much smaller proportion than those known to generalists. Beaver et al. (2000), in an interview study with 44 terminally ill cancer patients, carers and bereaved carers reports regular contact with district nurses by 61%, but only 18% reported regular contact with a Macmillan nurse. It appears that not all palliative care patients receive care from generalist or specialist services, and these studies make no linkage between referral and need.

Some studies look specifically at palliative care service usage by those with non-malignant diseases. One study in Western Australia found that only 8% of those with selected non-malignant conditions accessed any form of specialist palliative care (Rosenwax and McNamara, 2006). A study of patients with chronic obstructive pulmonary disease in the UK found that 10% of those who had died had been in contact with a district nurse and 34% had regular contact with a
general practitioner (Elkington et al., 2005). No information on access to specialist palliative care services was given. One UK study comparing service access patterns of patients with chronic obstructive airways disease and lung cancer found that lung cancer patients saw their general practitioners more often, and that 30% of them saw a palliative care nurse, whereas none of the patients with chronic obstructive airways disease accessed such palliative care services (Gore et al., 2000). Studies have also been conducted with people with dementia (6% in nursing home and 13% in home care service had been referred to hospice) (Mitchell et al., 2004), and motor neurone disease with 66% of patients referred to a hospice in their last month of life (Ganzini et al., 2002). Again, these last two studies are in the US, making comparisons with UK service use difficult. Again, however, it appears that few patients access palliative care services, and there is no estimation of whether these are the most needy patients, or those most likely to benefit from care.

Most studies focus on the use of palliative care services by those with cancer, essentially reflecting historical usage patterns. The results of different studies demonstrate that: 24% of patients received only community based specialist palliative care, 25% both hospital and community care, and 19% hospital specialist palliative care only (68% of patients therefore received some form of specialist palliative care) (Rosenwax and McNamara, 2006); 16% of patients with breast cancer received community follow up, and 18% had seen a general practitioner in the last six months of life (Gagnon et al., 2004); 7.5% of those dying of cancer in 1991 were referred to a palliative home care team (Costantini et al., 2003); 27% of patients with lung cancer and 20% of patients with colorectal cancer received hospice care before death (McCarthy et al., 2003a); 21% of those with a range of cancers received hospice care before death (McCarthy et al., 2003b). Fifty percent of those interviewed for a study of the determinants of the use of home hospice services had used hospice home care between study recruitment and death (Tang, 2003); 68% of patients dying from cancer in South Australia received hospice or palliative care services (Hunt et al., 2002); 43% of patients who had died from cancer and were over 65 in an area of the US used a hospice (Virnig et al., 2002); 50% of those dying of ovarian cancer in an area received hospice care (Yawn et al., 2001), and 28% of a sample of those who died from cancer received
care from a community specialist palliative care nurse (Addington-Hall and Altmann, 2000).

Other, older studies include Addington-Hall and McCarthy (1995), who found that 60% of the deceased people with cancer whose relatives/carers they interviewed had received care from a district nurse, 29% from a Macmillan nurse, and 81% had seen a general practitioner within a month of death. Gray and Forster (1997) also found that 30% of cancer patients who died in 1991 had used specialist palliative care services; 56% of patients in Australia had care from a hospice service (Hunt and McCaul, 1996); 41% of patients had used home care services (mostly home hospice) (McCusker, 1985); and 29% of those dying from cancer in one district were referred to a terminal care support team (Evans and McCarthy, 1984).

Difference and variation appears to be a key theme in these studies. Gray and Forster (1997) demonstrate differences in the proportions of patients referred to specialist palliative care from different general practices. This finding is echoed by Nash (1992), who found significant differences between mean referral rates of general practitioners to a palliative nursing service from the 29% who made no referrals in a given year, to the 45% who made between 2 and 5 referrals. This may reflect the different ways in which general practitioners use specialist palliative care, using them infrequently, as a resource, as part of their extended team, or handing over care (Shipman et al., 2002). Such differences may be influenced by their concerns about palliative care provision, explored in section 2.3.5.

A contrasting study method is employed in some studies which identify the numbers of those accessing particular palliative care services once they are already being cared for by a different service provider. For example, Faithfull et al. (2005) examine service use patterns of those with brain tumours referred to a comprehensive palliative care service. They found that 72% of those referred also accessed district nursing services, and 23% Marie Curie or sitting services. Such comparisons are also made by Grande et al. (2002), who compare service usage patterns for those who had and had not been referred to a hospital at home scheme. They found that patients referred to the scheme were consistently greater
users of other services such as district nursing (70% vs. 50%), Macmillan nursing (28% vs. 11%) and Marie Curie (22% vs. 3%). A study by Keegan et al. (2001) of relatives’ accounts of the last year of life, with a sample biased towards those receiving hospital based palliative care services, found 60% reported the use of nursing services at home. Twenty five percent of these had hospice and community nurse involvement, 58% just community nurse involvement. An earlier study into a palliative home care service found that 27% of their patients had no community nurse involvement. However, the most frequent visit contacts were between district nurses and patients (Hinton, 1996). It appears that being known to one form of general or specialist palliative care service may facilitate access to other services. It is unclear whether different usage patterns reflects some measure of patient need, whereby those in greatest need inevitably access a wider range of services, or reflects a system that promotes access to those who are already ‘known’ to one service.

It is difficult to form an overall conclusion from these studies. Although many use similar methods, particularly the use of retrospective record review to identify those who had received particular services compared to a population of those dying of the same disease, the different sample sizes, service provision patterns studied, and methods of determining the denominator make comparisons difficult. Older studies in particular use the number of cancer deaths in an area to determine the proportions of patients accessing community palliative care services. However, as increasing numbers of patients without cancer access services, particularly Medicare funded home hospice services in the US, such comparisons become more difficult.

There are consistent findings over a period of time indicating that no one service sees every patient in the palliative phase of their illness, and that some patients may not be referred to any palliative care services, particularly those providing specialist care. A key flaw in most studies is their reliance on routine, retrospective data which contains no information about clinical need for services, or potential benefits from referral. It is possible to know how many patients, or what proportions of patients are referred to particular services, but not whether these are the patients who may need or benefit most from care, or who may have wanted referral. Some studies collect data on issues related to need such as
symptom experience, but do not report any correlations between need and referral to specialist services, nor the timing of referral related to need (Tilden et al., 2004). Again, most studies also investigate use of specialist palliative care services, rather than the use of general services by those in the palliative phase of their illness. Information about the numbers of those accessing services is therefore meaningless in terms of policy or planning services, as it may be that such referrals are not required, not wanted, or have little impact on care outcomes.

There are increasing calls to make palliative care (especially specialist care) services available to all those who may need them, irrespective of diagnosis. This move from a traditional focus on cancer, whilst laudable in terms of equity, may be premature if there is still limited awareness of who may benefit from care. A position currently exists where there is awareness that not all patients are referred for care. However, it is not known why this situation exists, or whether those patients who could most benefit from care are being referred.
Table 2.4  Studies investigating how many patients are referred to community palliative care services

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<tr>
<th>Author, Date, Country</th>
<th>Research question/theme</th>
<th>Research approach</th>
<th>Participants</th>
<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
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<tbody>
<tr>
<td>Munn et al. (2006) US</td>
<td>To determine whether hospice use is associated with enhanced care</td>
<td>Interviews with staff and family members of residents in long term care facilities</td>
<td>124 family members and staff caregivers of those who died during a larger study</td>
<td>22% of deceased patients received hospice services before death (27% nursing home, 15% assisted living). Dementia less common in hospice enrollees</td>
<td>25 Looked at access to hospice care irrespective of diagnosis. No context given regarding type of hospice service</td>
</tr>
<tr>
<td>Rosenwax and McNamara (2006) Australia</td>
<td>To quantify the use of specialist palliative care during the last 12 months of life for people dying of cancer and selected-non cancer conditions</td>
<td>Retrospective analysis of routinely available data from three administrative databases (2000 – 2002)</td>
<td>26 882 people who died (aged over 1 day) during the study period formed total population, with 7 399 cancer deaths, 608 from cancer and specified non-cancer conditions, and 6712 deaths from specified non-cancer conditions</td>
<td>Cancer: 24% received only community specialist palliative care, 19% hospital based care, 25% both forms. Cancer and non-cancer: 20% community care, 13% hospital, and 15% both. Non-cancer: 3% community, 4% hospital, 1% both.</td>
<td>26 Useful breakdown over large population of disease type and access. No discussion of what type of community service offered</td>
</tr>
<tr>
<td>Casarett et al. (2005) US</td>
<td>To determine whether it is possible to increase hospice utilisation by identifying nursing home residents whose goals are consistent</td>
<td>A randomised controlled trial (2003 – 2004) of nursing home residents and their decision makers. Intervention: a</td>
<td>205 residents from three care homes, 107 randomly assigned to intervention, 98 received usual care</td>
<td>Intervention residents were more likely to enrol in hospice within 30 days (20% vs. 1%), or during follow up period (25% vs. 6%)</td>
<td>30 The nursing homes had closer relationships with hospice than general, so the</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
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<tr>
<td>Elkington <em>et al.</em> (2005) UK</td>
<td>To provide an account of the needs of COPD patients in the last year of life and their contact with services</td>
<td>Questionnaire survey of informants of COPD deaths over 2 months in 2001 in four health authorities</td>
<td>209 questionnaires returned (52% response)</td>
<td>10% had contact with a district nurse, 34% contact with a GP at least once a month, 5% contact with a respiratory nurse specialist</td>
<td>24 Population based approach important in highlighting those who are limited users of community services, although reliant on other’s recall</td>
</tr>
<tr>
<td>Faithfull <em>et al.</em> (2005) UK</td>
<td>To explore the referral and carer characteristics, symptoms and services of those with a primary malignant brain tumour</td>
<td>Retrospective case note review over 1 year (2002) of those with primary brain tumour referred to a palliative care service (inpatient, community, day hospice etc.)</td>
<td>39 case notes reviewed of 41 patients identified with the diagnosis from 1254 referrals that year</td>
<td>87% of referrals were for hospice community care rather than other hospice services. 72% of patients accessed district nursing services, 23% accessed Marie Curie/sitting services, 54% referred to social worker</td>
<td>24 Useful data on the use of general services for those who have been referred to a specialist service. Reliant on accurate note keeping</td>
</tr>
<tr>
<td>Fassbender <em>et al.</em> (2005) Canada</td>
<td>To evaluate the economic implications associated with Canadian innovations in the delivery of palliative care services</td>
<td>Retrospective analysis of routine data sources for patients who died of cancer in a region of Canada between 1993 and 2000</td>
<td>16282 adults died of cancer in this period</td>
<td>Utilisation of any (home care, hospice, acute consults etc.) palliative care service increased from 45% to 81%. Palliative homecare use increased from 44% to 57%</td>
<td>26 Acknowledged that some of the changes in use are due to different service provision patterns</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
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<tr>
<td>Lakasing and Mahaffey (2005) UK</td>
<td>To assess mortality patterns in one GP practice and assess nursing staff involvement in terminal care</td>
<td>Retrospective analysis of routine data sources for patients registered with the practice and dying in 2001-2002</td>
<td>116 deaths (from all causes) during the study period</td>
<td>28.4% of patients who died had involvement of the practice’s nursing staff in terminal care (33.8% of patients dying at home (incl RH and NH), 21.6% of patients dying elsewhere, average of 12 weeks of care)</td>
<td>20 No disaggregation of type of nursing care – practice or district nurses. No correlation of illness and type of nursing care. No definition of ‘involvement’</td>
</tr>
<tr>
<td>Lackan et al. (2004b) US</td>
<td>To examine whether variability in hospice use determined by patient characteristics has changed over time</td>
<td>Retrospective cohort design using routine data from linked Surveillance, Epidemiology and End Results – Medicare database to study hospice use.</td>
<td>170 136 people identified who were 67+, diagnosed between 1991-96, and who died between 1991 – 1999, with breast, colorectal, lung or prostate cancer.</td>
<td>30.2% of the studied population used hospice care before they died</td>
<td>27 Useful large study</td>
</tr>
<tr>
<td>Lackan et al. (2003) US</td>
<td>To assess the use of hospice by women dying with breast cancer as a function of time period, geographic area and patient characteristics.</td>
<td>Retrospective analysis of routine data from the linked Surveillance, Epidemiology and End Results – Medicare database to study hospice use.</td>
<td>25 161 women met the criteria: women 65+, diagnosed 1986-96, died 1991-1996.</td>
<td>20.7% enrolled in hospice before they died. Rate of hospice use increased from 11.5% in 1991 to 27.1% in 1996.</td>
<td>25 Large US study with no contextual factors, and integrating different forms of hospice care.</td>
</tr>
<tr>
<td>Gagnon et al. (2004)</td>
<td>To define the extent to which women dying of breast cancer had</td>
<td>Retrospective analysis of routine data sources for the</td>
<td>2 291 women were identified as dying from breast cancer</td>
<td>18% had received follow up by a general practitioner in the last 6 months of life,</td>
<td>26 The predefined indicators may not</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
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<tr>
<td>Canada</td>
<td>Access to palliative care years 1992 – 1998. Range of data sources used to determine access to palliative care, not just home care services.</td>
<td>16% some form of community follow up and 21% at least one home care visit. Pattern of care dominated by hospital model.</td>
<td>290 home care patients and 2730 nursing home patients who had full MDS assessments prior to death and were over 65</td>
<td>5.7% of nursing home patients referred to hospice, 13.1% of home care patients</td>
<td>26 One of few studies to look at palliative care use in a non-cancer population</td>
</tr>
<tr>
<td>Mitchell et al. (2004) US</td>
<td>To examine and contrast end of life experiences of severely demented people who died within one year of admission to either a nursing home or community based home care service</td>
<td>Retrospective study using routine MDS data</td>
<td>1578 respondents interviewed (65% of identified sample)</td>
<td>36.1% died without any nursing services, 12.4% had home nursing services and 51.5% had home hospice services</td>
<td>25 Reliant on carer reports of care and symptoms. Low response rate may have affected representativeness of sample</td>
</tr>
<tr>
<td>Teno et al. (2004) US</td>
<td>To evaluate the US dying experience at home and in institutions</td>
<td>Interviews with main carers of a sample of those who died in 2000 over 22 states</td>
<td>1189 care givers of older (65+) deceased patients who died in community settings between 2000 and</td>
<td>62.4% of those who died out of hospital were enrolled in hospice. 32% of deaths due to cancer.</td>
<td>25 Oregon has a very high home death rate of Medicare deaths, and this may make the results</td>
</tr>
<tr>
<td>Tilden et al. (2004) US</td>
<td>To examine the end of life experiences of elderly people dying out of hospital</td>
<td>Telephone survey of family caregivers 2 – 5 months after patients’ death</td>
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<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
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<tr>
<td>Costantini et al. (2003) Italy</td>
<td>To determine the effect of a palliative home care team (PHCT) on hospital utilisation in the 6 months before death</td>
<td>Quasi-experimental design using retrospective data from existing records for PHCT users and matched cancer controls</td>
<td>189 PHCT patients matched to 378 controls in one area of Italy in 1991</td>
<td>7.5% of those dying of cancer in 1991 were referred to the palliative home care team</td>
<td>29 PHCT functions not well described. Reports data a decade old. No power calculation</td>
</tr>
<tr>
<td>McCarthy et al. (2003a) US</td>
<td>To identify factors associated with hospice enrolment and length of stay in hospice in patients dying with lung or colorectal cancer</td>
<td>Retrospective analysis of routine data on Medicare beneficiaries diagnosed with lung or colorectal cancer and who died in 1998</td>
<td>62 117 lung cancer and 57 260 colorectal cancer patients aged over 66</td>
<td>27% of patients with lung cancer and 20% of patients with colorectal cancer received hospice care before death</td>
<td>26 No information known about hospice type or availability in this national study</td>
</tr>
<tr>
<td>McCarthy et al. (2003b) US</td>
<td>To examine whether receiving Medicare managed care insurance or fee for service insurance affected hospice use.</td>
<td>Retrospective analysis of routine data on Medicare beneficiaries diagnosed with a range of cancers and who died in 1998</td>
<td>260 090 deceased Medicare beneficiaries with cancer aged over 66.</td>
<td>21.1% received hospice care before death. Managed care patients more likely to use hospice (32.4% vs. 19.8%)</td>
<td>26 No information known about hospice type or availability in this national study</td>
</tr>
<tr>
<td>Tang (2003) US</td>
<td>To identify determinants of the use of hospice home care services for terminally ill cancer patients</td>
<td>Secondary analysis of data from terminally ill cancer patients participating in a prospective study identifying determinants of place</td>
<td>127 patients were interviewed, who subsequently died</td>
<td>50.4% had used hospice home care services between recruitment and death</td>
<td>26 No contextual description of services. Prospective design does not rely on recall or record</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
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<tr>
<td>Ganzini et al. (2002)</td>
<td>To study the health care experiences and palliative care needs of patients with ALS in their final month of life</td>
<td>Structured survey of caregivers of those who had died between 1995 – 1999 administered by telephone, face to face, or self completed</td>
<td>50 (of 91) caregivers participated.</td>
<td>66% of patients were enrolled in hospice in the last month of life</td>
<td>23 Small study, with a large non-response rate, all living in a similar geographical area. No information on what type of hospice services accessed</td>
</tr>
<tr>
<td>Burge et al. (2002)</td>
<td>To determine the rate of referral to a local palliative care programme</td>
<td>Retrospective study using routine data of all those dying in Halifax of cancer between 1992-7</td>
<td>4376 patients who died from cancer</td>
<td>Referral to the palliative care programme increased from 39% in 1992 to 62% in 1997</td>
<td>23 No explanation of the palliative care programme referred to</td>
</tr>
<tr>
<td>Grande et al. (2002)</td>
<td>To investigate the variables associated with referral to hospital at home for palliative care</td>
<td>Retrospective analysis of cancer deaths 1994-1995 of patients referred to service compared random sample of cancer deaths from routine records</td>
<td>121 deceased cancer HAH patients and 206 cancer registry patients</td>
<td>HAH (CR patients) patients: 70% (50%) had received DN care, 5% (2%) night nursing, 28% (11%) Macmillan, 22% (3%) Marie Curie</td>
<td>29 One of the few studies to track general as well as specialist service use. Some of the numbers using particular services are small</td>
</tr>
<tr>
<td>Hunt et al. (2002)</td>
<td>To examine the uptake of designated palliative care services</td>
<td>Retrospective review of cancer deaths in 1999 using routinely</td>
<td>3086 deceased cancer patients (2105 palliative care</td>
<td>68.2% of patients dying from cancer received hospice or palliative care</td>
<td>24 No disaggregation of patients by type of</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
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<tr>
<td>Todd <em>et al.</em> (2002) UK</td>
<td>To examine the views of health care professionals towards a hospice at home scheme</td>
<td>A survey of GPs and DNs whose patients were potential users of the hospice at home scheme 21/2 years after scheme commencement</td>
<td>61 DNs (85% response) and 136 GPs (65% response)</td>
<td>93% of DNs and 57% of GPs reported that they had had a patient referred to the service</td>
<td>25 Useful for providing data relating to generalists use of services. No data reported on the questionnaire itself or questions asked</td>
</tr>
<tr>
<td>Virnig <em>et al.</em> (2002) US</td>
<td>To examine whether rates of hospice use differ according to patient characteristics</td>
<td>Retrospective analysis of routine data on cancer deaths in the District of Columbia for those over 65 in 1996</td>
<td>Records relating to 169,759 hospice deaths and 388,511 cancer deaths</td>
<td>43.4% used hospice</td>
<td>23 No contextual discussion of what as meant by ‘hospice’</td>
</tr>
<tr>
<td>Keegan <em>et al.</em> (2001) Ireland</td>
<td>To investigate relatives’ retrospective accounts of aspect of health care in the last year of life</td>
<td>Semi-structured interview incorporating a critical incident technique</td>
<td>155 interviews (57% response) from a stratified sample of those dying in hospital 1996 - 1997</td>
<td>60% received nursing care at home: of these 25% hospice and community nurse, 58% community nurse alone, 9% hospice nurse alone</td>
<td>21 Sample biased towards those who had received hospital palliative care services, and based on hospital deaths</td>
</tr>
<tr>
<td>Yawn <em>et al.</em> (2001) US</td>
<td>To describe the epidemiology, management and care of ovarian cancer patients in a</td>
<td>Retrospective review of routine medical records of patients diagnosed between 1985 and 1997</td>
<td>107 women who had been diagnosed in this time period</td>
<td>50% of those dying of ovarian cancer received hospice care for a mean of 39 days before death</td>
<td>26 No contextual discussion of what hospice or other community services</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
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<tr>
<td>Addington-Hall and Altmann (2000) UK</td>
<td>How do patients who received care from community specialist palliative care nurses differ from those who do not</td>
<td>Data drawn from the Regional Study of Care for the Dying, interviews with randomly selected relatives of those who died in 1990 (see Addington-Hall and McCarthy 1995)</td>
<td>2062 relatives/friends of those who died from cancer</td>
<td>574 (27.8%) received care from a community specialist palliative care nurse</td>
<td>27 Reliant on reports of others as to care received</td>
</tr>
<tr>
<td>Beaver et al. (2000) UK</td>
<td>To provide insight into users’ perspectives of palliative care service provision</td>
<td>Semi-structured interviews with terminally ill patients and their carers recruited through general practices</td>
<td>15 terminally ill patients and their 10 lay carers, 19 bereaved carers</td>
<td>Wide variability in service provision reported. Overall regular (and occasional contact) with GPs for 34% (57%), DNs 61% (27%), Macmillan nurse 18% (43%), Social worker 2% (11%), Palliative care consultant 0% (4.5%)</td>
<td>24 Participants not randomly selected, so high probability that those who were high service users (and therefore recalled by PHCT gatekeepers) were more likely to be recruited</td>
</tr>
<tr>
<td>Gore et al. (2000) UK</td>
<td>To compare care for patients with COPD and lung cancer</td>
<td>Semi-structured interviews with patients incorporating quality of life instruments</td>
<td>50 (from 81) patients with COPD and 50 patients with NSCLC (from 96) compared</td>
<td>COPD saw GP 8.5 times a year (mean), NSCLC 10.7 (mean) p= 0.01. 30% of NSCLC patients saw a Marie Curie nurse, Macmillan nurse or hospice. No COPD patients received</td>
<td>29 Useful data because it includes non-cancer patients in the comparison. Has needs based data but does not relate to...</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>Hanson <em>et al.</em> (1999) US</td>
<td>To examine the frequency of life sustaining treatment use and describe what factors influence physicians’ treatment decisions</td>
<td>Telephone interview with family members of those 65+ who had died of cancer, congestive heart failure, chronic lung disease, cirrhosis or stroke and their physicians. Identified from consecutive death certificates 1994 – 5</td>
<td>461 (80% response) family members and 165 (69% response) physicians</td>
<td>such services. 24% COPD received ad hoc visits from respiratory support nurse. More COPD patients saw a District Nurse</td>
<td>24% COPD received ad hoc visits from respiratory support nurse. More COPD patients saw a District Nurse. No information given on context of care. No justification of sample size.</td>
</tr>
<tr>
<td>Hunt and McCaul (1998) Australia</td>
<td>To determine changes in proportion, types and usage patterns of hospice users over time</td>
<td>Retrospective analysis of hospice and population cancer deaths using routinely collected data in 1990 and 1993</td>
<td>2800 patients in 1990 (1239 hospice, 1561 non hospice), 2873 in 1993 (1060 hospice, 1813 non hospice)</td>
<td>34% were enrolled in hospice care.</td>
<td>No discussion of what is meant by hospice. No rationale for the choice of diagnoses.</td>
</tr>
<tr>
<td>Johnston <em>et al.</em> (1998) Canada</td>
<td>To assess the degree to which Nova Scotia cancer patients who may need palliative care are being referred to a comprehensive palliative care programme</td>
<td>Retrospective, population based study using routine administrative data for all adults who died between 1988 – 1994</td>
<td>14 494 adults died in study period, 2057 were registered with the palliative care programme</td>
<td>53% of patients accessing services in 1990, 63% in 1993</td>
<td>No disaggregation of data from different hospice types.</td>
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<td>14.2% of patients overall were registered with the PCT – this varied by location with 36.4% registered in Halifax County (closest to programme). No determination of use of different aspects of the palliative care programme (i.e.</td>
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<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
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<tr>
<td>Gray and Forster (1997) UK</td>
<td>To identify and compare those who received specialist palliative care and those who did not</td>
<td>Retrospective study of deceased cancer patients identified from death register, cross referenced with data from palliative care services records</td>
<td>521 patients who died in 1991 (157 received SPC, 354 did not)</td>
<td>Increase in county over time from 21% 1988, to 40% 1994</td>
<td>24 No disaggregation of data from different specialist palliative care services – including home care as well as other services</td>
</tr>
<tr>
<td>Hinton (1996) UK</td>
<td>To review care received by patients of one palliative home care service</td>
<td>Prospective study of patients referred to one palliative home care service incorporating routine data, patient interviews and professional interviews</td>
<td>77 randomly selected patients from 428 referred</td>
<td>30% of patients had used specialist palliative care services</td>
<td>22 Only data from one service, with little context given about the service. Needs data collected, but not related to visits. Assumption made that service is ‘competent’ with no supporting data</td>
</tr>
<tr>
<td>Hunt and McCaul (1996)</td>
<td>To determine the coverage of hospice care in South Australia, compare service and</td>
<td>Retrospective study based on record review and routinely collected data of all</td>
<td>2 800 deceased patients in South Australia in 1990, of whom 1561 had</td>
<td>56% of patients who died in 1990 had care from a hospice service</td>
<td>24 No disaggregation of data from different specialist palliative care services – including home care as well as other services</td>
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<tr>
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<th>Participants</th>
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<th>Appraisal of study and quality score</th>
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<tr>
<td><strong>Australia</strong></td>
<td>non-service users and evaluate the impact of hospice on place of death</td>
<td>deceased cancer patients</td>
<td>hospice involvement</td>
<td>care services – includes home care as well as other services</td>
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</tr>
<tr>
<td>Addington-Hall and McCarthy (1995) UK</td>
<td>To provide a contemporary account of care of the dying – focusing on care in the community</td>
<td>Structured interviews with deceased relatives about experiences of care of last year of life – sampled randomly from 20 health districts, with a bias to cancer deaths</td>
<td>2074 respondents of those who had died from cancer (71% response)</td>
<td>60% had care from district nurse, 29% from Macmillan nurse or similar. 29% needed some (if not received) or more (if received) home nursing than received. 81% saw GP within a month of death</td>
<td>27 Retrospective view of carers may mis-represent patients’ views, but is likely to be more representative of dying patients than prospective studies</td>
</tr>
<tr>
<td>Costantini et al. (1993) Italy</td>
<td>To investigate changes in proportions of home deaths, characteristics of patients receiving care, determinants of place of death, and impact of palliative home care services on home deaths</td>
<td>Retrospective analysis of routinely available data for those dying of cancer in Genoa between 1986 and 1990</td>
<td>12 343 cancer deaths were studied.</td>
<td>Proportion of patients assisted by palliative home care service increased from 1.6% (1986), to 8.0% (1990)</td>
<td>26</td>
</tr>
<tr>
<td>Cartwright (1991a) UK</td>
<td>To report on the differences in end of life care over a period of 18 years</td>
<td>Interviews with key informants of people who had died in 10/12 areas of England</td>
<td>785 interviews (82% response) in 1969 and 639 (80% response) in 1987</td>
<td>GPs: A reduction in the number of home visits (23% 20+ visits vs. 11%) and consultations (29% 20+ vs. 19%). DN: Approx 30% had been visited in the year before</td>
<td>23 No data relating diagnosis to use of general services. No data on use of specialist palliative care services</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<td>Research approach</td>
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<tr>
<td>McCusker and Stoddard (1987) US</td>
<td>To evaluate a home palliative care programme</td>
<td>Quasi – experimental time series evaluation using routine death and service use data collected before during and after implementation of home palliative care service</td>
<td>1874 deceased under 65 year old residents of one area – cancer deaths – 1976 -1982</td>
<td>death in both studies, but length of time increased. Proportion seen daily decreased</td>
<td>26 Users who died within one month of diagnosis excluded, and only claims within last 6 months of life included. Only studied under 65 years</td>
</tr>
<tr>
<td>McCusker (1985) US</td>
<td>To identify factors associated with the use of home care/home hospice by patients with terminal cancer</td>
<td>Structured interview with relatives of those who had died from cancer in one area between 1979 and 1980.</td>
<td>133 eligible patients. 96 interviews (72% response) with relatives of those who had died from cancer. 122 (92%) interviews with their doctors</td>
<td>41% had used home care services (mostly home hospice)</td>
<td>25 Study of satisfaction with services may be affected by the retrospective nature of the data</td>
</tr>
<tr>
<td>Evans and McCarthy (1984) UK</td>
<td>Information about the workings of a terminal care support team (home and hospital)</td>
<td>Retrospective record review of referred patients compared to death certification records</td>
<td>125 referred patients who lived within the district compared to 437 cancer deaths overall</td>
<td>55% of those dying in one area were referred to the team, and 29% of the cancer deaths in the whole district</td>
<td>21</td>
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2.3.3 Which patients are referred to community palliative care services?

Identifying the characteristics of patients referred to community palliative care services is a well researched area, with over fifty studies identified. Generally, studies compare patients referred to a community palliative care service either with those enrolled in a different form of palliative care service, or some estimation of the palliative care/terminal care cancer population. A judgement is then made about the impact of particular patient characteristics on the likelihood of referral (Grande et al., 1998). For the purposes of this review these patient characteristics are grouped into three areas: demographic characteristics (age, gender, ethnicity, and marital status), social characteristics (socio-economic information, carer information) and medical characteristics (diagnosis and functional status). The results of the studies are summarised in relation to these themes in table 2.5, and an overview of each of the studies given in table 2.6 in more detail.

2.3.3.1 Demographic information

Age

Studies reporting the mean or median age of patients referred to community palliative care services demonstrate that most patients receiving palliative care services are in early old age (e.g. 69 years (Chen et al., 2003) 70 years (Costantini et al., 2003), 66 years (Potter et al., 2003), 68 years (Skilbeck et al., 2002), 72 years (Tyrer and Exley, 2005), 73 years (Casarett and Abraham, 2001)), and a large survey of hospice care in the US demonstrates that 69% of patients were over 65 years of age (Jones and Strahan, 1997).

However, more relevant to access issues is whether such median ages reflect the ages of those who may benefit from palliative care. Studies consistently demonstrate that the likelihood of being referred to community specialist palliative care services varies with age. Twenty six studies listed in table 2.6 demonstrate that younger patients are more likely to be referred to palliative care services than a comparator population. There are also some studies which
demonstrate the opposite: that older patients are more likely to be referred (Berry et al., 1994; Christakis and Iwashyna, 2000; Miller et al., 2003; Chen et al., 2003; Gagnon et al., 2004). Other studies demonstrated no impact of age on referral (Mor et al., 1985; Sessa et al., 1996; Banaszak-Holl and Mor, 1996; Costantini et al., 1999; Higginson and Wilkinson, 2002; Costantini et al., 2003; Potter et al., 2003; Ahlner-Elmqvist et al., 2004).

Some of this difference might be related to different comparisons being made to either reference populations of those who may need care, or with those receiving other forms of care. However within these typologies, many different approaches were reviewed: using different reference populations, comparing different hospice types, comparing hospice and hospital etc. It may be that some of the differences are an artefact of the comparison made, particularly when comparisons across studies are complicated by the very different structures, settings and operational procedures of the palliative and general care services studied. However, no consistent trend depending on comparison made can be determined: two of the studies finding that older people were more likely to be referred make a comparison to a general population (Berry et al., 1994; Gagnon et al., 2004), the other three make a comparison across palliative care providers (Christakis and Iwashyna, 2000; Miller et al., 2003; Chen et al., 2003).

Whilst the evidence does point to older people being less likely to be referred to or use home based specialist palliative care services, it is hard to discern why this is. A recent systematic review considering the impact of age on referral to specialist palliative care services suggests that the issue of inequality versus inequity is not explored (Burt and Raine, 2006). They suggest that the differential is inequitable only if elderly peoples’ healthcare needs are the same as those who are younger. It may be that older people may have fewer complex palliative care symptoms or needs (Addington-Hall et al., 1998a; Walsh et al., 2000; Lidstone et al., 2003). A study of those admitted to a palliative home care service has found that those under 70 were more likely to use opioids and ante-emetics, and were more likely to have metastases (De Conno et al., 2002). Whilst drug usage may be an artefact of prescription habits, not need, the higher incidence of metastases may indicate different patterns of need. Those who are older may
also be less likely to need help with distressing symptoms, but some do have very distressing symptoms (Armes and Addington-Hall, 2003).

The needs of older people may be well met by generalists such as district nurses and general practitioners. However, the analysis of Grande et al. (2002) demonstrates that patients not referred to a Hospital at Home scheme are also less likely to be receiving most other forms of care such as district nursing, hospital admission, hospice inpatient or night nursing. Another hypothesis is that older people have different attitudes towards palliative care which may affect their use of services. This has been investigated, however, and found not to affect care (Catt et al., 2005).

A further hypothesis is that it is carer’s age, not patient’s age which affects access to services. One study has demonstrated that carer age is as important a predictor of palliative home care use as patient age, hypothesising that younger carers may have greater support needs, or show greater effectiveness in obtaining help (Grande et al., 2006). This is a relatively small study in comparison to some of the larger population-based studies, but the hypothesis warrants further investigation.

Whilst it appears that older patients are less likely to access services, the reasons for this are not clear cut, and it may not necessarily reflect inequality, but differences in need.

**Gender**

The evidence about whether gender affects referral to palliative care services is equivocal, with studies split on whether gender had an impact. Many studies conclude that gender does not influence referral to community palliative care services (McCusker, 1985; Costantini et al., 1993; Hunt and McCaul, 1996; Sessa et al., 1996; Gray and Forster, 1997; Hunt and McCaul, 1998; Addington-Hall and Altmann, 2000; Higginson and Wilkinson, 2002; Grande et al., 2002; Hunt et al., 2002; Costantini et al., 2003; Potter et al., 2003; Rosenwax and McNamara, 2006).
Of those studies which did identify a difference, the majority reported that women were more likely to be referred (or men less likely) (Mor *et al*., 1985; McCusker and Stoddard, 1987; Berry *et al*., 1994; Banaszak-Holl and Mor, 1996; Christakis and Iwashyna, 2000; Virnig *et al*., 2002; Tang, 2003; McCarthy *et al*., 2003a; Lackan *et al*., 2004b; Solloway *et al*., 2005; Burge *et al*., 2005a). Only a few studies reported the converse, that men were more likely to be referred (or women less likely) (Komesaroff *et al*., 1989; Greiner *et al*., 2003).

It may be that there is a slight tendency for women to be referred more readily to community palliative care services, but again few hypotheses for why this may be so have been raised. As with the data regarding age above, it may be that carer gender has as much impact as patient gender. This is explored further when examining marital status and carer support.

**Ethnicity**

Ethnicity as a variable of study is frequently omitted from studies of patient characteristics. It is more frequently found in studies from the US, perhaps because ethnicity is a more prominent policy issue (Loury *et al*., 2005). In contrast, in the UK, Higginson and Wilkinson (2002) report that whilst only 2% of patients referred to Marie Curie were non-white, 30% of patients had missing ethnicity data. In addition, they were unable to make a comparison with their reference dataset because ethnicity was not recorded within it. Skilbeck *et al*. (2002) also report that 14% of referrals to Macmillan nurses had missing ethnicity data, but where data was recorded only 4% were non-white, and for 7 of the 12 sites studied no non-white patients were recorded. This issue of poor ethnic monitoring is criticised by Hill and Penso (1995), in their report on access to palliative care services by members of black and ethnic minority communities.

Of the studies reporting ethnicity, 5 studies found that ethnicity had no impact on referral patterns (Greer *et al*., 1986; Casarett and Abrahm, 2001; Casarett, 2001; Hunt *et al*., 2002; Welch *et al*., 2005). All but one (Hunt *et al*. 2002) are studies from the US. One study found that Hispanics are significantly less likely to use hospice than non-Hispanic whites, but that this difference disappears after
adjustments for age, marital status, sex, educational attainment, income, area of residence and type of insurance were made (Lackan et al., 2004a).

Studies finding that those from black and ethnic minority populations are less likely to access palliative care services include studies reporting that African Americans are less likely to access care (Greiner et al., 2003; Miller et al., 2003), that black patients are less likely to access care (Virnig et al., 2002), that non-white, non-black patients use services less (McCarthy et al., 2003a), or that non-white patients are less likely to be referred (Banaszak-Holl and Mor, 1996; Fountain, 1999; Karim et al., 2000; O'Mara and Arnella, 2001). Australian studies have either found that those of non Australian descent are more likely to access care (Hunt and McCaul, 1998; Peters and Sellick, 2006), or that indigenous people are less likely to access care (Rosenwax and McNamara, 2006).

Only one study reports that non-white patients had a referral advantage (Christakis and Iwashyna, 2000). This study primarily investigates referral timing, and found that non-white patients enrolled in hospice (mostly home hospice) four days earlier than white patients. There is evidence that when home care specifically is studied, non-white patients may be more likely to be referred, when compared to other forms of palliative care. Mor et al. (1985) found that non-white patients are more likely to be referred to home hospice care than hospital hospice care, as did Eve et al. (1997). This finding echoes that of Karim et al. (2000), in their interview study of referrals from general practitioners to hospice services. They found that general practitioners are more likely to refer members of ethnic groups to home based hospice than in-patient hospice because they feel that home care services are more compatible with the families wish to care for the patient and home, and that that such patients have little grasp of the concept of hospice. There is also an indication that hospital and home care services have a different response to the needs of different ethnic groups. Koffman et al. (2003) found that general practitioners (but not hospital doctors) are reported to have tried less hard to manage symptoms in black Caribbean patients.

These studies indicate that ethnicity may have an impact on referral decisions, but with a caveat based on the work of Lackan (2004a), to suggest that some of
these differences may not only be because of ethnicity per se, but also that those from black and ethnic minority communities may differ in their age structures, income levels, places of residence etc. which could impact on the use of palliative care services. There are many differences between the cultures and contexts of these studies, particularly different issues surrounding ethnic origin in the UK and US. As with the earlier data on age, there are no data given on any estimation of need, or the patients’ ability to benefit from services, and so it is difficult to judge whether the different access patterns are related to systematic bias, differential need, or some other factor.

2.3.3.2 Social information

Marital status

Most of the studies reporting marital status find that being married increases the likelihood of being referred to home specialist palliative care (McCusker, 1985; Komesaroff et al., 1989; Dunphy and Amesbury, 1990; Costantini et al., 1993; Berry et al., 1994; Addington-Hall and Altmann, 2000; Casarett and Abrahm, 2001; Casarett, 2001; Yang et al., 2001; Greiner et al., 2003; Miller et al., 2003; Solloway et al., 2005; Peters and Sellick, 2006; Rosenwax and McNamara, 2006). Whilst there are a few studies finding no difference (Gray et al., 1987; Hunt and McCaul, 1996; Hunt and McCaul, 1998; Costantini et al., 2003), no studies find that being married decreases the likelihood of being referred.

Many authors conclude that marital status is a proxy variable for having a carer at home. This is discussed further when investigating carer data, and the presence of a carer in the home.

Carers

Most studies demonstrate that variables which increase the probability of having home based informal carers improve the likelihood of patients being referred to palliative care services, whilst living alone decreases the likelihood (Mor et al., 1985; Greer et al., 1986; Bradshaw, 1993; Addington-Hall and Altmann, 2000; Casarett and Abrahm, 2001; Greiner et al., 2003; Miller et al., 2003; Chen et al.,
2003; Peters and Sellick, 2006). The U.S. National Hospice Study, when investigating further those with a primary carer, found that if the carer was employed, this decreases the likelihood of referral (Greer et al., 1986, Mor et al., 1985). Mor et al. (1985) found that if the carer were male, this decreases the likelihood of referral. The perception of whether the family have the ability to achieve home as a preferred place of death can also affect referrals (Tang, 2003). One variable which may affect this perception is the age of the carer, and a recent study demonstrates that those with younger carers are more likely to receive Marie Curie or Macmillan nursing support (Grande et al., 2006).

These findings appear to lend support to the hypothesis that those referred to palliative care services are those assumed to have sufficient support to facilitate home care, whether this is a spouse (especially a female spouse), or other carer. For US studies this may reflect the criteria of many home hospice services requiring there to be an informal carer before a referral is made. This raises questions about the burden a carer would be expected to shoulder at home, and whether the care provided after a referral meets the expectations of both the carer and patient.

**Socio-economic characteristics**

Studies investigating referral use a variety of different descriptors to investigate the impact of socio-economic characteristics. These include educational levels, home owning, health insurance, income and deprivation.

Four studies found that having a lower educational level increases the likelihood of referral to specialist palliative care (Casarett and Abrahm, 2001; Yang et al., 2001; Costantini et al., 2003; Chen et al., 2003). However, two studies found the converse, that those with the greater educational levels are more likely to access care (Costantini et al., 1993; Greiner et al., 2003) and one study found that education had no influence (Christakis and Iwashyna, 2000).

The studies which point to the influence of income are less equivocal, with most studies examining income finding that those receiving high to middle income levels are more likely to access care (Berry et al., 1994; Casarett and Abrahm,
Several studies investigate the impact of type or place of residence on access, finding that those who own their own homes (Addington-Hall and Altmann, 2000; Greiner et al., 2003), who live in less deprived areas (Grande et al., 2002) or who do not live in rural areas (Hunter et al., 1998; Hunt et al., 2002; McCarthy et al., 2003a; Rosenwax and McNamara, 2006) are more likely to access care.

The data on health insurance are difficult to interpret. Some studies find that those without health insurance are more likely to access care (Casarett and Abrahm, 2001; Casarett, 2001; Peters and Sellick, 2006), or those who do not have a particular type of insurance (fee for service insurance) (McCarthy et al., 2003a). One study found that those with Medicare are more likely to access care (Welch et al., 2005).

Komesaroff et al. (1989) found that professional, non-manual and sedentary workers are more likely to be referred. Two studies found no effect on referral of ‘social class’ (Gray and Forster 1997) or ‘socioeconomic factors’ (Gray et al., 1987).

Whilst data on the impact of socio-economic factors on referral is not clear cut, the trend from these studies indicates that those who may be anticipated to have fewer socioeconomic disadvantages are more likely to access care. As with other factors, such findings only point to the existence of inequity in referrals, not the reason. It may be that referrers are making choices based on whom they feel may be better able to be cared for and supported at home, which could prioritise those who have the financial and social means to support themselves more effectively. An alternative explanation could be that people with such characteristics are better equipped to seek out or request specialist support in the home. No studies reviewed went further than the descriptions here to investigate these or other hypotheses, usually again because they are reliant on the use of routinely collected, retrospective data. Again, there is a real need to explore the reasons behind these apparent inequities further.
2.3.3.3 Medical information

Diagnosis

It is important to note that most of the diagnoses discussed in studies are cancer diagnoses, as the studies reported here focus almost exclusively on cancer patients. Of the 33 studies investigating the patients' primary cancer diagnosis, nine found that the diagnosis had no impact on the likelihood of referral to specialist palliative home care (Mor et al., 1985; Komesaroff et al., 1989; Banaszak-Holl and Mor, 1996; Gray and Forster, 1997; Costantini et al., 1999; Higginson and Wilkinson, 2002; Costantini et al., 2003; Potter et al., 2003; Solloway et al., 2005).

Of the studies finding a diagnosis effect, results are very inconclusive for most cancer diagnoses. The picture is perhaps clearest for those with haematological malignancies with a number of studies finding that such a diagnosis (i.e. leukaemia, lymphoma, myeloma) reduces the likelihood of referral (Evans and McCarthy, 1984; McCusker and Stoddard, 1987; Hunt and McCaul, 1996; Sessa et al., 1996; Johnston et al., 1998; Hunt and McCaul, 1998; Addington-Hall and Altmann, 2000; Hunt et al., 2002). Other diagnoses found to reduce the likelihood of referral include brain cancer (Addington-Hall and Altmann, 2000), and other CNS tumours (Dunphy and Amesbury, 1990). Having lung cancer appears to increase the likelihood of referral (Evans and McCarthy, 1984; Dunphy and Amesbury, 1990; Costantini et al., 1993).

For other cancer diagnoses, studies present more conflicting evidence. For example having a gastrointestinal cancer can reduce (Evans and McCarthy, 1984) or improve (Addington-Hall and Altmann, 2000) referral. Similar findings are found in oropharyngeal cancers with reductions (Talmi et al., 1997) or improvements (Evans and McCarthy, 1984) in referral, and prostate cancer with Hunt et al. (2002) identifying it as a diagnosis with fewer referrals than expected, in contrast to Costantini et al. (1993). Having breast cancer too presents a confusing picture with some studies identifying fewer referrals (Evans and McCarthy, 1984; Sessa et al., 1996; Hunt et al., 2002), and others more
Most of these studies report on the likelihood of referral for those with cancer, far fewer studies estimate the likelihood of referral for those with non-malignant disease. One study identifies that those with non-malignant disease are less likely to be referred to a hospital at home scheme (Grande et al., 2002), and another that those who have substance abuse problems, psychiatric disease or dementia are likely to be referred to a hospice earlier (Christakis and Iwashyna, 2000).

Although the results are not conclusive, it seems that those with haematological and brain tumours are less likely to access specialist home care, and those with lung cancers are more likely to access care. This may reflect that services are better able to care for those with commoner cancers, a different pattern of service provision within haematology, or different patterns of need associated with different diagnoses. A study of the opinions of haematologists towards referral to specialist palliative care service identifies three barriers: logistical concerns (difficulties referring to palliative care services in the past); medical concerns (lack of experience of palliative care services in managing those with haematological malignancies) and the difficulties of prognostication (Auret et al., 2003).

It is also notable that the diagnoses explored are mostly cancer diagnoses, not addressing the needs of the 5% of patients referred currently who do not have a cancer diagnosis, and the large pool of potential referrals for those in the palliative phase of other illnesses (Addington-Hall et al., 1998b). Research into referral of patients with non-cancer diagnoses to palliative care services indicates that people are willing to refer to specialist palliative care services, particularly in the hospital setting (Kite et al., 1999; Dharmasena and Forbes, 2001). This intention however, seems to translate into a much smaller number of actual referrals. Rosenwax and McNamara (2006) found that whilst 68% of those who died from cancer during their study period had contact with a specialist palliative care team, only 8% of those with selected non cancer conditions had such contact, a dramatic difference. Kite et al. (1999) identify that patients
without cancer referred to the home care team had advanced disease and short prognoses, and conclude that identifying when a terminal stage has been reached proves difficult for referrers – a conclusion which resonates with the research above relating likelihood of referral to increased time from diagnosis to death.

Again, whilst this research demonstrates apparent inequity in referrals, it may be that those with different diagnoses have different needs which could be met in different ways. In particular the needs of those with malignant and non-malignant diseases may differ considerably, and there is little research indicating whether such different referral patterns reflect bias or need.

**Functional status**

The evidence about whether the functional status of patients affects referral is equivocal. It is particularly difficult to compare results across studies, not only because of the different contexts and comparisons noted earlier, but also because of the range of different measures of functional status used. Some studies indicate that patients referred to specialist palliative home care are less well on a number of measures (Greer et al., 1986; Dunphy and Amesbury, 1990; Addington-Hall and Altmann, 2000; Miller et al., 2003; Chen et al., 2003; Ahlner-Elmqvist et al., 2004). Other studies indicate that it tends to be more able, fitter patients who are referred to community palliative care services (Gray et al., 1987; Bradshaw, 1993; Talmi et al., 1997; Tang, 2003; Peters and Sellick, 2006). Mor et al. (1985) found no correlation between referral and functional status.

These findings are of concern. First, many studies investigating the impact of patient characteristics on referral do not incorporate a measure of functional status. Whilst there may be many reasons, one explanation is the reliance of many of these studies on a retrospective analysis of routinely available data which may not incorporate information on functional status. Second, functional status should be a key indicator of referral. Commentators and policy documents suggest that the key criterion for referral should be an assessment of need. Functional status is likely to be one characteristic which indicates need, and yet
this appears to be a significantly under researched area (Ahmed et al., 2004; NICE, 2004).

2.3.3.4 Summary

This review indicates that people with certain characteristics are more likely to access specialist palliative home care. For example, younger, married, wealthier people with a carer at home appear to be more likely to be referred. This information is summarised in table 2.5, where the characteristics above are explicitly presented for each study.

However there is little information about why those referring patients, or patients themselves, are making these choices. A recent review of the literature on age and access makes criticisms of those studies which are applicable to many studies reviewed in this section; they have inadequate descriptions of specialist palliative care services; and the quality of outcomes data is often poor, relying on retrospective investigations of use, routine data or proxy recall, but where there could be inconsistent recording or the validity of proxies could be questioned, and questions asked of proxies insufficiently comprehensive (Burt and Raine, 2006).

In addition to such criticisms, whilst these studies raise awareness of the differential use of palliative care services, they do little to aid understanding of the reasons for such differences. Hypothesised reasons, such as differences in abilities for patients or carers to request services, different needs of patients, different assessments of ability to cope at home, or systematic bias in referral practices, have not yet been thoroughly investigated. Such a lack of understanding is also highlighted in the broader referral literature, particularly that investigating the referrals general practitioners make to hospital specialists. Patient characteristics may explain a small amount of the variation in these referral practices, but it is concluded that most variation is still unexplained, with more in-depth qualitative studies needed, rather than the survey designs which predominate in that field (Wilkin and Smith, 1987; King et al., 1994; O'Donnell, 2000).
This literature also focuses almost exclusively on access and utilisation patterns within specialist palliative care services. There is little information available about the patterns of access of patients to general palliative care, with only one study looking at the patient characteristics which influenced visits from a family physician (Burge et al., 2005a). Those providing general care such as general practitioners and district nurses may be critical to access patterns, not only providing much care in the community, but also referring patients to specialist care. It may be the choices these referrers make, and whether the specialist teams choose to accept a referral, which affects these patterns of access, and which could be important to investigate.
Table 2.5 Summary of the themes of research investigating which patients are referred to community palliative care services
(Key: + indicates more likely to be referred with that characteristic, - less likely, 0 no effect found, N/A characteristic not studied).

<table>
<thead>
<tr>
<th>Author, date, country</th>
<th>Demographic information</th>
<th>Social information</th>
<th>Medical information</th>
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<tbody>
<tr>
<td></td>
<td>Age</td>
<td>Ethnicity</td>
<td>Gender</td>
</tr>
<tr>
<td>Grande et al. (2006) UK</td>
<td>Receiving Marie Curie/Macmillan nurse care younger +</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Peters and Sellick (2006) Australia</td>
<td>Older -</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Rosenwax and McNamara (2006) Australia</td>
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<td>Indigenous -</td>
<td>Gender 0</td>
</tr>
<tr>
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<td>N/A</td>
<td>N/A</td>
<td>Females +</td>
</tr>
<tr>
<td>Author, date, country</td>
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<td>Social information</td>
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<td></td>
<td>Age</td>
<td>Ethnicity</td>
<td>Gender</td>
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<tr>
<td>Luckan et al. (2005) US</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Solloway et al. (2005) US</td>
<td>Younger + (compared to nursing home)</td>
<td>N/A</td>
<td>Male – (compared to hospital)</td>
</tr>
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<td>N/A</td>
<td>African-American 0</td>
<td>N/A</td>
</tr>
<tr>
<td>Ahner-Elmqvist et al. (2004) Sweden</td>
<td>Age 0</td>
<td>N/A</td>
<td>N/A</td>
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<td>N/A</td>
<td>N/A</td>
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<tr>
<td>Gagnon et al.</td>
<td>Older age +</td>
<td>N/A</td>
<td>N/A</td>
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<td>Author, date, country</td>
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<tr>
<td>(2004) US</td>
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<td></td>
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<tr>
<td>Lackan et al. (2004a) US</td>
<td>N/A</td>
<td>Hispanic vs. Non-Hispanic White 0</td>
<td>N/A</td>
</tr>
<tr>
<td>Lackan et al. (2004b) US</td>
<td>Younger +</td>
<td>Non-Hispanic White +</td>
<td>Female +</td>
</tr>
<tr>
<td>Chen et al. (2003) US</td>
<td>Older age +</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Costantini et al. (2003) Italy</td>
<td>Age 0</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Greiner et al. (2003) US</td>
<td>Younger +</td>
<td>African American -</td>
<td>Female -</td>
</tr>
<tr>
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<td>Younger +</td>
<td>Ethnicity 0</td>
<td>N/A</td>
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<td>Author, date, country</td>
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<tr>
<td></td>
<td>Age</td>
<td>Ethnicity</td>
<td>Gender</td>
</tr>
<tr>
<td>McCarthy et al. (2003a) US</td>
<td>N/A</td>
<td>Non white, non black -</td>
<td>Male -</td>
</tr>
<tr>
<td>McCarthy et al. (2003b) US</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>Miller et al. (2003) US (likelihood of receiving continuous hospice home care)</td>
<td>Younger than 65 -</td>
<td>African-American -</td>
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<tr>
<td>Potter et al. (2003) UK</td>
<td>Age 0</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Tang (2003) US</td>
<td>N/A</td>
<td>N/A</td>
<td>Female +</td>
</tr>
<tr>
<td>Burge et al. (2002)</td>
<td>Younger</td>
<td>N/A</td>
<td>N/A</td>
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<td>Author, date, country</td>
<td>Demographic information</td>
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<td></td>
<td>Age</td>
<td>Ethnicity</td>
<td>Gender</td>
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<tr>
<td>Canada</td>
<td>age +</td>
<td></td>
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<tr>
<td>Grande et al. (2002) UK</td>
<td>Younger age +</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Hunt et al. (2002) Australia</td>
<td>80 or older –</td>
<td>Race 0</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Higginson and Wilkinson (2002) UK</td>
<td>Age 0, but older patients received fewer hours of care</td>
<td>No comparison possible (68% white, 2% other, 30% missing data)</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Skilbeck et al.</td>
<td>Younger</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>(2002) UK</td>
<td>age +</td>
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<tr>
<td>Virnig et al. (2002) US</td>
<td>Younger than 80 +</td>
<td>Black</td>
<td>Male</td>
</tr>
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<td>Referrals from academic centre younger +</td>
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<tr>
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<td>‘bridge’ referrals younger +</td>
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<td>Ethnicity -</td>
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<td>Younger age +</td>
<td>N/A</td>
<td>Gender 0</td>
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<td>Age</td>
<td>Ethnicity</td>
<td>Gender</td>
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<tr>
<td>Christakis and Iwashyna (2000) US (referring to earlier referral to hospice)</td>
<td>Older age +</td>
<td>Nonwhite +</td>
<td>Women +</td>
</tr>
<tr>
<td>Karim et al. (2000) UK</td>
<td>N/A</td>
<td>Non-white -</td>
<td>N/A</td>
</tr>
<tr>
<td>Costantini et al. (1999) Italy</td>
<td>Age 0</td>
<td>N/A</td>
<td>Female admitted to hospice, not home pcu +</td>
</tr>
<tr>
<td>Fountain (1999) UK</td>
<td>N/A</td>
<td>Non-white -</td>
<td>N/A</td>
</tr>
<tr>
<td>Hunt and McCaul (1998) Australia</td>
<td>Aged 40 – 60+ 80 or older -</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Johnston et al. (1998) Canada</td>
<td>Younger age +</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Author, date, country</td>
<td>Demographic information</td>
<td>Social information</td>
<td>Medical information</td>
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<td></td>
<td>Age</td>
<td>Ethnicity</td>
<td>Gender</td>
</tr>
<tr>
<td>Eve <em>et al.</em> (1997) UK</td>
<td>N/A</td>
<td>Ethnic minority + (compared to in patient care)</td>
<td>N/A</td>
</tr>
<tr>
<td>Gray and Forster (1997) UK</td>
<td>Younger age +</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Talmi <em>et al.</em> (1997) Israel</td>
<td>Younger +</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Banaszak-Holl and Mor (1996) US</td>
<td>Age 0</td>
<td>White +</td>
<td>Female +</td>
</tr>
<tr>
<td>Hunt and McCaul (1996) Australia</td>
<td>Age 40-50 +, 80 and over -</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Sessa <em>et al.</em> (1996) Switzerland</td>
<td>Age 0</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Berry <em>et al.</em> (1994)</td>
<td>Older +</td>
<td>N/A</td>
<td>Female +</td>
</tr>
<tr>
<td>Author, date, country</td>
<td>Demographic information</td>
<td>Social information</td>
<td>Medical information</td>
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<td></td>
<td>Age</td>
<td>Ethnicity</td>
<td>Gender</td>
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<tr>
<td>US.</td>
<td></td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Bradshaw (1993)</td>
<td>Younger age +</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Australia</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Costantini et al.</td>
<td>Younger age +</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>(1993) Italy</td>
<td></td>
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<tr>
<td>Dunphy and Amesbury</td>
<td>Younger age +</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>(1990) UK</td>
<td></td>
<td></td>
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<tr>
<td>Komesaroff et al.</td>
<td>Younger patients +</td>
<td>N/A</td>
<td>Males +</td>
</tr>
<tr>
<td>(1989) Australia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gray et al. (1987)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Australia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McCusker and Stoddard</td>
<td>N/A</td>
<td>N/A</td>
<td>Women +</td>
</tr>
<tr>
<td>(1987) US</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greer et al. (1986)</td>
<td>N/A</td>
<td>Race 0</td>
<td>N/A</td>
</tr>
<tr>
<td>Author, date, country</td>
<td>Demographic information</td>
<td>Social information</td>
<td>Medical information</td>
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<tr>
<td></td>
<td>Age</td>
<td>Ethnicity</td>
<td>Gender</td>
</tr>
<tr>
<td>Mor et al. (1985) US</td>
<td>Age 0</td>
<td>White</td>
<td>Men</td>
</tr>
<tr>
<td>McCusker (1985) US</td>
<td>Younger age +</td>
<td>N/A</td>
<td>Gender 0</td>
</tr>
<tr>
<td>Evans and McCarthy (1984) UK</td>
<td>Younger age +</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Table 2.6  
Studies investigating which patients are referred to community palliative care services

<table>
<thead>
<tr>
<th>Author, Date, Country</th>
<th>Research question/theme</th>
<th>Research approach</th>
<th>Participants</th>
<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grande et al. (2006)  UK</td>
<td>To investigate how both patient and carer age relate to palliative care use, controlling for relevant variables</td>
<td>Structured interview with bereaved carers of those referred to a hospital at home service during a randomised controlled trial. Additional data collected from routine sources</td>
<td>123 carers (57% response)</td>
<td>Patients who received Marie Curie and Macmillan nursing were younger and had younger carers. Those receiving Marie Curie and hospice care more likely to have cancer. Macmillan care recipients more likely to be in lower occupational classes and have carers who had reduced or stopped work</td>
<td>25 Study only considers those who have already been selected to receive one service (Hospital at home). Relatively small sample</td>
</tr>
<tr>
<td>Peters and Sellick (2006) Australia</td>
<td>To compare patients receiving in patient and home based palliative care on a number of dimensions</td>
<td>Structured interview based questionnaire to patients with terminal cancer recruited from palliative care centres in 1999</td>
<td>58 patients (from a random sample of 93) (32 (71% response) in patients, 26 (54%) home based)</td>
<td>Home care patients more likely to be married, of non-Australian descent and without health insurance. More home care patients lived with someone, fewer over 80 although not statistically significant.</td>
<td>29 Small sample with poor recruitment, particularly of home care patients. No real description of the contexts of care provided</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
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<td>Findings/outcomes</td>
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<tr>
<td><strong>Rosenwax and McNamara (2006)</strong> Australia</td>
<td>To quantify the use of specialist palliative care during the last 12 months of life for people dying of cancer and selected non-cancer conditions</td>
<td>Retrospective analysis of routinely available data from three administrative databases (2000 – 2002)</td>
<td>26 882 people who died (aged over 1 day) during the study period formed total population, with 7 399 cancer deaths, 608 from cancer and specified non-cancer conditions, and 6712 deaths from specified non-cancer conditions</td>
<td>Fewer home care patients reported diarrhoea, appetite loss or belching. Lower home care score for symptom measures. Higher home care score for personal control</td>
<td>26 Useful breakdown over large population of disease type and access. No discussion of what type of community service offered</td>
</tr>
<tr>
<td><strong>Burge et al. (2005b)</strong> Canada</td>
<td>To examine the association between patient income and residence and receipt of family physician visits during the end</td>
<td>Retrospective secondary analysis of linked population based data</td>
<td>7 212 patients who died of lung, colorectal, breast or prostate cancer between 1992 and 1997 in Nova Scotia</td>
<td>45% received at least one home visit. Most likely for those in middle to high income neighbourhoods, particularly outside</td>
<td>25 Data restricted to those with particular cancer diagnoses</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
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<tr>
<td>Lackan et al. (2005) US</td>
<td>To investigate the association between marital status and hospice use in the US</td>
<td>Retrospective analysis of routine data from the Surveillance, Epidemiology and End Result (SEER) – Medicare database</td>
<td>71 948 subjects with breast, colorectal, lung or prostate cancer diagnosed 1991-1996, died between 1991 – 1998. 28 779 (41%) used hospice</td>
<td>Hospice use greatest for married people. Significant interaction between marital status and gender suggests married males, married or ever married females more likely to use hospice</td>
<td>24</td>
</tr>
<tr>
<td>Solloway et al. (2005) US</td>
<td>To determine if the experience of dying differed among settings in New Hampshire</td>
<td>Retrospective state-wide analysis of adult deaths in hospitals, nursing homes and homecare/hospice agencies in 2 months in 2002</td>
<td>782 deaths reported (424 hospital, 148 nursing home, 210 home care/hospice) – 44% of adult deaths during study period</td>
<td>Significant differences among settings for mean age, gender, marital status, primary insurance, diagnosis, Advance directives, symptom assessment and provision of emotional and spiritual support</td>
<td>22</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
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<tr>
<td>Tyrer and Exley (2005) UK</td>
<td>To evaluate a new hospice at home scheme</td>
<td>Retrospective analysis of routinely collected data about those accessing the service</td>
<td>155 patients accessed the service in 2003</td>
<td>Population 52% male, median age 72, 83% white, 92% with cancer and were 68% already residing at home</td>
<td>22 No comparison with population of those not using HAH made</td>
</tr>
<tr>
<td>Welch et al. (2005) US</td>
<td>To compare the end of life care received by African-American and white decedents and their families</td>
<td>Cross-sectional retrospective telephone survey with surrogates for decedents over 22 states (adult, non-traumatic deaths)</td>
<td>1578 interviews (65% response) including 111 African-American decedents</td>
<td>No statistically difference between African-Americans and white decedents in rates of receiving hospice care during the last month of life</td>
<td>27 Reliant on proxy reports of care. African Americans were underrepresented in the study</td>
</tr>
<tr>
<td>Ahlner-Elmqvist et al. (2004) Sweden</td>
<td>To compare patients receiving either hospital based advanced home care or conventional hospital care</td>
<td>Prospective non-randomised study, with patients allocated according to their preferences over a 2 ½ year period</td>
<td>722 patients referred, of which 297 enrolled in study. 119 AHC group and 178 CC group</td>
<td>Two groups comparable in terms of socio-demographic characteristics. More CC patients had a higher Karnofsky performance index. Median time from diagnosis to inclusion greater for AHC group, with shorter survival after enrolment</td>
<td>26 Self selection of participants to arms of care may have affected differences, but in a way which would be mirrored in non-study choices</td>
</tr>
<tr>
<td>Currow et al. (2004)</td>
<td>To investigate a whole population method for</td>
<td>Questions on palliative care use included in annual</td>
<td>3027 interviews conducted (70% response)</td>
<td>47% indicated that SPCS was involved in care of someone</td>
<td>25 No definitions of what was meant by</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>Australia</td>
<td>determining palliative care need</td>
<td>random face to face cross sectional survey of 4 400 people in South Australia</td>
<td>close to them who had died. No difference in access by country of birth, educational level or residential. Higher income indicated higher use</td>
<td>palliative care service. High numbers of people did not know whether palliative care service had been used</td>
<td></td>
</tr>
<tr>
<td>Gagnon et al. (2004)</td>
<td>To define the extent to which women dying of breast cancer had access to palliative care</td>
<td>Retrospective analysis of routine data sources for the years 1992 – 1998. Range of data sources used to determine access to palliative care, not just home care services</td>
<td>2 291 women were identified as dying from breast cancer</td>
<td>Younger women (&lt;50) less likely to receive care than middle aged women, older women (+70) more likely</td>
<td>26 The predefined indicators may not indicate palliative care. The context of care could not be specified</td>
</tr>
<tr>
<td>Lackan et al. (2004b)</td>
<td>To examine whether variability in hospice use determined by patient characteristics has changed over time</td>
<td>Retrospective cohort design using routine data from linked Surveillance, Epidemiology and End Results – Medicare database to study hospice use</td>
<td>170 136 people identified who were 67+, diagnosed between 1991-96, and who died between 1991 – 1999, with breast, colorectal, lung or prostate cancer</td>
<td>Hospice use varied significantly by patient characteristics. Hospice use more likely if enrolled in managed care, younger, married, female, non-Hispanic white, living in urban areas, diagnosed with lung or colorectal</td>
<td>27 Useful large study, which indicates that variability in use may be decreasing with the expansion of services over time</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>Lackan et al. (2004a)</td>
<td>To investigate rates of hospice use between Hispanic and non-Hispanic white Medicare beneficiaries</td>
<td>Retrospective cohort study using routine data from the linked SEER – Medicare database</td>
<td>34,336 subjects, 67+, with breast, colorectal, lung or prostate cancer, diagnosed 1991-96, died 1991 – 1998</td>
<td>Hispanic and non-Hispanic Whites use hospice services at similar rates. A difference (in favour of whites) was found in unadjusted model, but disappeared in adjusted model</td>
<td>26 SEER areas are different in some ways to other areas of US study only looked at older adults</td>
</tr>
<tr>
<td>Chen et al. (2003)</td>
<td>To identify factors that may influence hospice decision</td>
<td>Cross sectional structured interview with patients within one community based hospice, and three teaching hospitals</td>
<td>234 patients with lung, breast, prostate or colon cancer (173 hospice, 61 non hospice)</td>
<td>Patients receiving hospice care were older, less educated, had more people in the household, more co-morbid conditions and worse activities of daily living scores.</td>
<td>26 Only looking at specific cancers</td>
</tr>
<tr>
<td>Costantini et al. (2003)</td>
<td>To determine the effect of a palliative home care team on hospital utilisation in the 6 months before death</td>
<td>Quasi-experimental design using retrospective data from existing records for PHCT users and matched cancer</td>
<td>189 PHCT patients matched to 378 controls in one area of Italy in 1991</td>
<td>No difference in age, gender, most demographic variables. More likely to be referred to PHCT if lower</td>
<td>29 PHCT functions not well described. Reports data a decade old. No power calculation</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td><strong>Greiner et al.</strong> (2003) US</td>
<td>To examine racial/ethnic variations in rates of hospice use in a national cohort</td>
<td>Secondary analysis of the 1993 national mortality followback survey. (telephone survey with proxy respondents)</td>
<td>11 291 individuals who died in 1993</td>
<td>Being married, having a higher income, having some college education, being younger, having high levels of social support, associated with hospice use. Being female, not owning a home and being African American negatively associated with hospice use</td>
<td>27 Use of proxy respondents may have affected accuracy. Very large sample</td>
</tr>
<tr>
<td><strong>Lackan et al.</strong> (2003) US</td>
<td>To assess the use of hospice by women dying with breast cancer as a function of time period, geographic area and patient characteristics</td>
<td>Retrospective analysis of routine data from the linked Surveillance, Epidemiology and End Results – Medicare database to study hospice use</td>
<td>25 161 women met the criteria: women 65+, diagnosed 1986-96, died 1991-1996</td>
<td>20.7% enrolled in hospice before they died. Use of hospice care inversely related to age and higher amongst those who were married. No differences in use by ethnicity. Rates of use varied by geographic area</td>
<td>25 No information known about hospice type or availability in this national study.</td>
</tr>
<tr>
<td><strong>McCarthy et al.</strong></td>
<td>To examine whether</td>
<td>Retrospective</td>
<td>260 090 deceased</td>
<td>More likely if a</td>
<td>26</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>(2003b) US</td>
<td>receiving Medicare managed care insurance or fee for service insurance affected hospice use</td>
<td>analysis of routine data on Medicare beneficiaries diagnosed with a range of cancers and who died in 1998</td>
<td>Medicare beneficiaries with cancer aged over 66</td>
<td>managed care patient</td>
<td>No information known about hospice type or availability in this national study</td>
</tr>
<tr>
<td>McCarthy et al. (2003a) US</td>
<td>To identify factors associated with hospice enrolment and length of stay in hospice in patients dying with lung or colorectal cancer</td>
<td>Retrospective analysis of routine data on Medicare beneficiaries diagnosed with lung or colorectal cancer and who died in 1998</td>
<td>62,117 lung cancer and 57,260 colorectal cancer patients aged over 66</td>
<td>Later hospice enrolment for men, non-white, non-black race, having fee-for-service insurance, residing in a rural community</td>
<td>26 No information known about hospice type or availability in this national study</td>
</tr>
<tr>
<td>Miller et al. (2003) US</td>
<td>Whether timing of hospice referral is associated with continuous hospice home care</td>
<td>Retrospective study of routinely collected patient data from 21 hospice programs (same provider organisation)</td>
<td>28,747 service using patients who died between 1998 – 1999</td>
<td>Less likely to receive continuous hospice care if have hospice stay of less than 7 days, if younger than 65, if African-American or if have a caregiver at home vs. living alone. More likely to receive continuous hospice care if married, in severe pain.</td>
<td>30 Useful, large, comparison across many different sites country wide. No data on need</td>
</tr>
<tr>
<td>Potter et al. (2003) US</td>
<td>To describe patients referred to different components of</td>
<td>Retrospective case note review of 400 consecutive referrals</td>
<td>400 patients whose case notes were reviewed</td>
<td>No difference between groups for age, sex or diagnosis</td>
<td>23 The accuracy and comparability of the</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>UK</td>
<td>palliative care services (inpatient hospice, inpatient hospital, community team, outpatients)</td>
<td>to three palliative care centres</td>
<td></td>
<td></td>
<td>note taking between the teams participating was not assessed</td>
</tr>
<tr>
<td>Tang (2003)</td>
<td>To identify determinants of the use of hospice home care services for terminally ill cancer patients</td>
<td>Secondary analysis of data from terminally ill cancer patients participating in a prospective study identifying determinants of place of death (recruited from 6 sites, convenience sample)</td>
<td>127 patients were interviewed, who subsequently died</td>
<td>More likely if longer length of survival, family perceived ability to achieve preferred place of death, home as realistic preferred place of death, female, lower levels of functional dependency, use of emergency care in final days of life</td>
<td>26 No contextual description of services. Prospective design does not rely on recall or record keeping accuracy</td>
</tr>
<tr>
<td>Burge et al. (2002)</td>
<td>To determine the rate of referral to a local palliative care programme</td>
<td>Retrospective study using routine data of all those dying in Halifax of cancer between 1992-7</td>
<td>4376 patients who died from cancer</td>
<td>Less likely if older than 65 years</td>
<td>23 No explanation of the palliative care programme referred to</td>
</tr>
<tr>
<td>Grande et al. (2002)</td>
<td>To investigate the variables associated with referral to hospital at home for palliative care</td>
<td>Retrospective analysis of cancer deaths 1994-1995 of patients referred to service compared</td>
<td>121 deceased cancer HAH patients and 206 cancer registry patients</td>
<td>More likely to be referred to HAH if younger, less deprived, longer diagnosis time, died</td>
<td>29 One of the few studies to track general as well as specialist service use</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<td>Research approach</td>
<td>Participants</td>
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<tr>
<td>Higginson and Wilkinson (2002) UK</td>
<td>To describe and evaluate the care provided by Marie Curie nurses</td>
<td>Retrospective analysis of routine data collected by Marie Curie and cancer death registrations in England</td>
<td>26632 requests for a Marie Curie nurse made in 26 months</td>
<td>No difference in age, main diagnosis or gender when compared to cancer deaths recorded with ONS</td>
<td>22 Data from UK for referrals compared to English registry data, no comment on comparability</td>
</tr>
<tr>
<td>Hunt et al. (2002) Australia</td>
<td>To examine the uptake of designated palliative care services</td>
<td>Retrospective review of cancer deaths in 1999 using routinely collected data</td>
<td>3086 deceased cancer patients (2105 palliative care service users, 981 non users)</td>
<td>Less likely if 80 or older, country residents, with survival from diagnosis to death of &lt; 3 months, those with prostate, breast or haematological malignancy. More likely if from UK, Ireland or Southern Europe</td>
<td>24 No disaggregation of patients by type of palliative care service accessed</td>
</tr>
<tr>
<td>Virnig et al. (2002) US</td>
<td>To examine whether rates of hospice use differ according to patient characteristics</td>
<td>Retrospective analysis of routine data on cancer deaths in the District of Columbia for those over 65 in 1996</td>
<td>Records relating to 169 759 hospice deaths and 388 511 cancer deaths</td>
<td>Less likely if black or male. More likely if younger than 80</td>
<td>23 No contextual discussion of what as meant by ‘hospice’</td>
</tr>
<tr>
<td>Casarett</td>
<td>To determine whether</td>
<td>Retrospective cohort</td>
<td>All 1691 patients</td>
<td>More likely if younger,</td>
<td>26</td>
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<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>Casarett and Abrahm (2001) US</td>
<td>differences exist between patients referred to hospice (inpatient and homecare) from academic or non academic centres</td>
<td>study</td>
<td>admitted to the hospice between 1997 – 1999 who had then died or been discharged. 411 had been referred from an academic centre</td>
<td>higher incomes. Less likely with Medicare or Medicaid</td>
<td>No disaggregation of homecare of inpatient care data</td>
</tr>
<tr>
<td>Casarett and Abrahm (2001) US</td>
<td>To compare patients enrolled in a bridge program with those enrolled in hospice</td>
<td>Retrospective study of all patients admitted to the programs between 1997 – 1999 from routinely collected data</td>
<td>284 patients enrolled in the bridge program and 1 000 enrolled in hospice</td>
<td>Bridge patients less likely to have Medicaid/care, were younger, more likely to be married, and more likely to be in highest income category. No difference in the number of needs</td>
<td>26 Program described does not appear to be replicated in the literature elsewhere so transferability unclear</td>
</tr>
<tr>
<td>O’Mara and Arenella (2001) US</td>
<td>To determine the hospice coverage of care by racial and ethnic group</td>
<td>Retrospective analysis of routinely collected patient data compared to state-wide mortality data</td>
<td>2191 patients cared for during 1997 by one US hospice (home care and inpatient)</td>
<td>The hospice cared for 31% of Caucasians who died, 19% of Hispanics, 20% African Americans, 20% Asians in the area. For cancer, 52% Caucasians, 40% Hispanics, 40% African- Americans and 48% Asians</td>
<td>24 No description of context of hospice studied or the area in which it is sited. Very small numbers of ethnic minority patients represented in the data reported (85% Caucasian use)</td>
</tr>
<tr>
<td>Yang et al.</td>
<td>To determine the</td>
<td>Cross-sectional study</td>
<td>123 patients: 26</td>
<td>Significant difference</td>
<td>20</td>
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<tr>
<th>Author, Date, Country</th>
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<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
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<tbody>
<tr>
<td>(2001) Taiwan</td>
<td>impact of different hospice care patterns on outcomes of care for terminal cancer patients</td>
<td>design with purposive sample of patient and nurses from five medical centres in Taiwan. (2 inpatient and home care, 1 home hospice and consultation, 1 home hospice and 1 acute care only)</td>
<td>patients receiving inpatient hospice, 26 consultations, 23 home hospice, 38 conventional acute care</td>
<td>in age (home hospice younger than inpatient, older than acute care), education (less likely to have high school or higher), marital status (more likely to be married than acute care patients, less likely than team consultation) and primary care givers (less likely to be spouse than team consultation) across the groups</td>
<td>No description given of purposive sampling or the biases in recruitment this could have introduced. Very poor presentation of demographic characteristics</td>
</tr>
<tr>
<td>Addington-Hall and Altmann (2000) UK</td>
<td>How do patients who received care from community specialist palliative care nurses differ from those who do not</td>
<td>Data drawn from the Regional Study of Care for the Dying, interviews with randomly selected relatives of those who died in 1990</td>
<td>2062 relatives/friends of those who died from cancer</td>
<td>More likely if dependent, breast cancer, under 75 yrs. Less likely haematological malignancy, dependent for more than year</td>
<td>27 Reliant on reports of others as to care received</td>
</tr>
<tr>
<td>Christakis and Iwashyna (2000)</td>
<td>To identify individual and market factors associated with the timing of hospice use</td>
<td>Retrospective review of routinely collected Medicare, census and area data</td>
<td>151 410 Medicare funded hospice enrollees admitted to all hospices in 1993</td>
<td>Earlier hospice enrolment for nonwhites, women, older people, those</td>
<td>27 No disaggregation of data on in-patient and home hospice care.</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<tr>
<td>US</td>
<td></td>
<td></td>
<td>and followed up until 1999</td>
<td>with substance abuse, psychiatric disease or dementia. No association with income or education</td>
<td>Analysis only on elderly Medicare patients, but is very large cohort and covers 80% of hospice population. No data on need</td>
</tr>
<tr>
<td>Karim <em>et al.</em> (2000)</td>
<td>To examine the use of palliative care service by members of black/ethnic minority communities</td>
<td>Retrospective analysis of referrals to one hospice in Birmingham, and interviews with doctors about referral practices</td>
<td>1681 referrals to hospice in 1996/7. 27 doctors (12 GPs from 24 and 15 hospital consultants from 22)</td>
<td>144 (8.5%) of referrals for patients of BEM origin, compared to 21.5% BEM population</td>
<td>22 Most of the GPs who did not take part were of South Asian origin and this may have affected the results, explanation of sampling limited</td>
</tr>
<tr>
<td>Costantini <em>et al.</em> (1999)</td>
<td>To develop a staging system for terminal cancer patients, validated against survival</td>
<td>Multicentre (58) prospective study of a random sample of admissions to palliative care units (Mostly home or mixed hosp/home units)</td>
<td>601 patients of 3901 registered patients (22%) referred over 6 months in 1995</td>
<td>No difference in age or cancer site between referrals to different units, but females less likely to be admitted to home palliative care unit</td>
<td>27 Appropriate method, although extending recruitment period may have resulted in better data. No data on need</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<tr>
<td>Fountain (1999) UK</td>
<td>To examine the use of all specialist palliative care services in Derby by people from ethnic minorities over one year</td>
<td>Retrospective comparison of ethnicity data on referred patients compared to census data</td>
<td>1035 patients referred to specialist palliative care services</td>
<td>Only 1.5% of referrals were from ethnic minorities compared to 4.6% for the overall catchment area</td>
<td>16 No real description of how the study was carried out, or of differences between type of specialist palliative care provider</td>
</tr>
<tr>
<td>Hunt and McCaul (1998) Australia</td>
<td>To determine changes in proportion, types and usage patterns of hospice users over time</td>
<td>Retrospective analysis of hospice and population cancer deaths using routinely collected data in 1990 and 1993</td>
<td>2800 patients in 1990 (1239 hospice, 1561 non hospice), 2873 in 1993 (1060 hospice, 1813 non hospice)</td>
<td>Less likely if elderly, rural resident, haematological malignancy. More likely if 40 – 60 yrs, longer survivor and born in UK or Europe</td>
<td>24 No disaggregation of data from different hospice types</td>
</tr>
<tr>
<td>Johnston et al. (1998) Canada</td>
<td>To assess the degree to which Nova Scotia cancer patients who may need palliative care are being referred to a comprehensive palliative care programme</td>
<td>Retrospective, population based study using routine administrative data for all adults who died between 1988 – 1994</td>
<td>14 494 adults died in study period, 2057 were registered with the palliative care programme</td>
<td>More likely to be enrolled in PCP if resident in Halifax County, younger, having received palliative radiotherapy, had head and neck cancer. Less likely with haematological malignancy or lung cancer</td>
<td>25 No determination of use of different aspects of the palliative care programme (i.e. home care). No assessment of need for care</td>
</tr>
<tr>
<td>Eve et al.</td>
<td>To survey specialist</td>
<td>Questionnaire survey</td>
<td>Data from 149 (75%)</td>
<td>Home care patients</td>
<td>21</td>
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<tr>
<td>Author, Date, Country</td>
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<tr>
<td>(1997) UK</td>
<td>palliative care services about their provision during 1994/5</td>
<td>to all known providers in the UK</td>
<td>in patient units, 235 (68%) home care services, 168 (81% day care units)</td>
<td>more likely to be from ethnic minorities</td>
<td>No comparison made of characteristics across different types of units for most characteristics</td>
</tr>
<tr>
<td>Gray and Forster (1997) UK</td>
<td>To identify and compare those who received specialist palliative care and those who did not</td>
<td>Retrospective study of deceased cancer patients identified from death register, cross referenced with data from palliative care services records</td>
<td>521 patients who died in 1991 (157 received specialist palliative care, 354 did not)</td>
<td>More likely if younger, survived longer, had particular GP practice</td>
<td>24 No disaggregation of data from different specialist palliative care services – including home care as well as other services</td>
</tr>
<tr>
<td>Jones and Strahan (1997) US</td>
<td>To present a summary of data collected in the 1994 National Home and Hospice Care Survey</td>
<td>A probability survey of home and hospice care organisations provided information on their characteristics, current patients and discharges</td>
<td>61,000 patients were receiving hospice care at the time of the survey</td>
<td>Described current patients without reference to non hospice patients or other comparators: 55% female, 81% white, 69% over 65, 48% married, and 64% live with family members</td>
<td>- Data summary only so no quality score. Comprehensive data source for raw data on hospice use, but no disaggregation by type of hospice</td>
</tr>
<tr>
<td>Talmi et al. (1997) Israel</td>
<td>To compare the head and neck cancer populations in in-patient and home based hospice programmes</td>
<td>Retrospective study of head and neck cancer patients admitted to one hospice between 1988 and 1994 using</td>
<td>102 (from 118) inpatients and 24 (from 25) home hospice patients studied</td>
<td>Home hospice patients were younger, with lower pain levels, less weight loss and less candidiasis. Fewer</td>
<td>21 No statistical analyses of significance of findings, no power calculation. Some</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<td>Research approach</td>
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<tr>
<td>Banaszak-Holl and Mor (1996) US</td>
<td>To compare patient characteristics in four different hospice programmes (hospital based, skilled nursing facility, home health agency and freestanding) between 1987 - 1990</td>
<td>Retrospective random sample of hospice beneficiaries identified from the continuous Medicare history sample (a 5% random sample of all Medicare beneficiaries) between 1987 – 1990</td>
<td>11750 beneficiaries were identified</td>
<td>Home health hospice more likely if female, white. No difference on diagnosis or age</td>
<td>24 Very large sample size</td>
</tr>
<tr>
<td>Hunt and McCaul (1996) Australia</td>
<td>To determine the coverage of hospice care in South Australia, compare service and non-service users and evaluate the impact of hospice on place of death</td>
<td>Retrospective study based on record review and routinely collected data of all deceased cancer patients</td>
<td>2 800 deceased patients in South Australia in 1990, of whom 1561 had hospice involvement</td>
<td>Less likely if 80 or older, lived in rural area or had haematological malignancy. More likely if survival time over 6 months, born in UK or Europe</td>
<td>24 No disaggregation of data from different specialist palliative care services – includes home care as well as other services</td>
</tr>
<tr>
<td>Sessa et al. (1996) Switzerland</td>
<td>To describe the characteristics of patients seen by a home care service</td>
<td>Retrospective analysis of clinical data of patients who died between 1991 and 1993 in Ticino</td>
<td>993 patients from 1223), of whom 317 participated in the home care programme</td>
<td>Characteristics of home care users similar to overall sample, but with fewer diagnoses of haematological</td>
<td>24 Little contextual information on services provided given</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<tr>
<td>Berry et al. (1994) US</td>
<td>To develop a better understanding of the determinants of selection of final site of care (community hospice vs. hospital) for terminally ill patients with lung cancer</td>
<td>Retrospective study of lung cancer deaths in Clark County in 1986 using routine data from death certificates and the cancer registry</td>
<td>251 patients (from 328 deaths) in 1986</td>
<td>Community hospice death more likely if have a spouse, if female, have higher income, if older, if being cared for by a family practitioner</td>
<td>20 Data on characteristics is related to time of death, not time of referral</td>
</tr>
<tr>
<td>Costantini et al. (1993) Italy</td>
<td>To investigate changes in proportions of home deaths, characteristics of patients receiving care, determinants of place of death, and impact of palliative home care services on home deaths</td>
<td>Retrospective analysis of routinely available data for those dying of cancer in Genoa between 1986 and 1990.</td>
<td>12 343 cancer deaths were studied</td>
<td>More likely if younger, married, higher educational level, lung, breast or prostate cancer</td>
<td>26</td>
</tr>
<tr>
<td>Dunphy and Amesbury (1990)</td>
<td>To identify characteristics which may distinguish between home care</td>
<td>Retrospective review of patients using routinely collected data</td>
<td>404 in-patient hospice patients and 143 home care patients who either died or</td>
<td>Homecare referral more likely if younger, married, with lung cancer. Less likely</td>
<td>23 Little description of data analysis procedures</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<td>Research approach</td>
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<td>Findings/outcomes</td>
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<tr>
<td>UK</td>
<td>and inpatient hospice patients</td>
<td>were discharged from one hospice in 6 months in 1988. with CNS tumours. Homecare group more dyspnoeic and depressed.</td>
<td>243 patients (108 in-patient, 135 home care)</td>
<td>Homecare group were younger, had partners, not to be pensioners and to have private insurance, and longer median survival</td>
<td>23 One of the first studies to identify the differences between home care and inpatient patients at referral. Allocation to programmes made by the hospice, not referrer, and this bias not addressed</td>
</tr>
<tr>
<td>Komesaroff <em>et al.</em> (1989) Australia</td>
<td>To study patients admitted to the inpatient and homecare component of a hospice programme</td>
<td>Prospective analysis of patients admitted to either programme over 12 months between 1985 – 1986</td>
<td></td>
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<tr>
<td>Gray <em>et al.</em> (1987) Australia</td>
<td>To compare the costs of a home hospice palliative care service with conventional terminal care</td>
<td>Retrospective analysis of routine data</td>
<td>98 deceased patients from the home service (1983) and 98 deceased matched controls</td>
<td>No difference in marital or socioeconomic status. More likely with longer mean survival time</td>
<td>22 Only looked at last 90 days. Assumption made that controls would be matched in terms of symptoms which may be false</td>
</tr>
<tr>
<td>McCusker (1985) US</td>
<td>To identify factors associated with the use of home care/home hospice by patients with terminal cancer</td>
<td>Structured interview with relatives of those who had died from cancer in one area between 1979 and 1980</td>
<td>133 eligible patients. 96 interviews (72% response) with relatives of those who had died from cancer. 122 (92%) interviews with their doctors</td>
<td>More likely if younger, married, longer terminal care period, spend more time at home</td>
<td>25 Study of satisfaction with services may be affected by the retrospective nature of the data</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
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<tr>
<td>Mor et al. (1985) US</td>
<td>To compare characteristics of patients admitted to hospital based hospice with those admitted to home based hospice.</td>
<td>Prospective data collection from routine records of admissions to home or hospital based hospice where a choice existed between the two</td>
<td>5912 patients (3446 hospital, 2466 home) in 17 (9 hospital, 8 home) hospices in 10 distinct geographical areas</td>
<td>Home hospice less likely choice than hospital hospice for females, those living alone, coming from a minority ethnic group, those using IV care, and those dependent in bowel and bladder care. Age, functional status and type of cancer not related</td>
<td>23 Timing of referral/ length of stay data not fully discussed. 30 mile radius for choices appears larger than would be practicable</td>
</tr>
<tr>
<td>Evans and McCarthy (1984) UK</td>
<td>Information about the workings of a terminal care support team (home and hospital)</td>
<td>Retrospective record review of referred patients compared to death certification records.</td>
<td>125 referred patients who lived within the district compared to 437 cancer deaths overall.</td>
<td>More likely if younger. Less likely with gastrointestinal, breast, haematological cancer, more likely oropharyngeal or lung cancer</td>
<td>21</td>
</tr>
</tbody>
</table>
2.3.4 What reasons are given for referral to community palliative care services, and who makes these referrals?

The literature reviewed about reasons for referral to palliative care services focuses on referral to specialist palliative care services and is summarised in table 2.7.

The most common reasons for referrals to community specialist palliative care services are consistently identified as the control of pain and other physical symptoms, and provision of care relating to psychosocial needs. There is no consensus on whether physical or psychological issues are more likely to provoke referral. Some studies identified elements of psycho-social care as the most common reasons for refundal, with studies identifying 64% (Fellowes et al., 2003), 57% (Skilbeck et al., 2002), 83% (Bennett et al., 2000), and 68% (Nash, 1993) of referrals for such reasons. However, other studies identified the control of pain and other physical symptoms as the most common primary reason for referral to specialist palliative care (McCarthy, 1990; Kite et al., 1999; Low et al., 2001; Kuin et al., 2004; Groot et al., 2005b).

There is recognition that many patients are referred to such services with more than one reason for referral identified, and ‘complex’ patients have been identified as those who have more than one need at referral, or where the referring professional is unable to provide appropriate care (Bestall et al., 2004). It has also been identified that the primary reasons given for referral can vary between services. Skilbeck et al. (2002) found, for example, that the proportion of patients referred for emotional care to Macmillan nurses ranged from 79% in one site to 4% in another. Whilst these were hospital not community Macmillan teams, it is possible that this difference in referral patterns equally exists in community health care. Researchers investigating reasons for referral tend to focus on symptom experience as a reason for referral, and most of the above studies list symptoms or groups of problems as reasons. Such studies therefore reveal little about what the specific issues are regarding such problems or symptoms which trigger a referral.
Such reasons for referral identified in these few studies appear in concordance with the wider range of studies identified which report research into patients’ symptom experiences. Such studies are outside the scope of this review, as they do not address an aspect of access, however it is fair to note that research again either identifies physical or psycho-social symptoms as most prevalent (Addington-Hall and Altmann, 2000; Bruera et al., 2000; Casarett and Abraham, 2001; Potter et al., 2003). Patients in the community also appear to have a number of symptoms, with one study finding an average of 7 per patient (Potter et al., 2003). It is perhaps unsurprising therefore that patients are referred for multiple reasons.

What is striking is how few studies investigate this aspect of referral, in contrast with the many studies reviewed looking at the characteristics of referred patients. There may be several explanations. It is possible that reasons for referral are less frequently routinely recorded, and as many studies rely on such records, this would affect collection of these data. Studies may focus on the problems and symptoms patients’ experience, rather than those given as a reason for referral between services. Researchers tend to focus on whether referrals are equitable, rather than the reason given for referral. Whatever the reason for this gap in the literature, it remains the case that there is much less known about the reasons professionals give for referring patients than about the characteristics of the patients who are referred.

An equally small number of studies investigating specialist community palliative care services indicate the source of referrals. A study of palliative care nurse specialists indicates that the majority of referrals come from a hospital source, either nurses (32%) or doctors (28%) (Skilbeck et al. 2002). District nurses and general practitioners referred 13% of patients, outpatient clinics 8%, and other clinical nurse specialists 11%. Very few referrals came directly from the patient or their family (3%). These referral patterns were similar across hospital and community teams, and Skilbeck et al. (2002) suggest that patients appear to be referred during a period of hospital treatment.

This trend is also noted by Evans and McCarthy (1984) almost 20 years earlier, noting that hospital consultants refer 36% of patients compared with GPs 16%. However, other studies of community specialist palliative care, whilst
demonstrating a number of hospital originated referrals, show that a community health care professional is the most frequent referrer to a community based palliative care service (Costantini et al., 1999; Dunphy and Amesbury, 1990; Kite et al., 1999; McCarthy 1990).

It appears that whilst referrals from outside the community may in some instances provide many referrals to specialist community palliative care services, referrals from within the community are also a major source of patients. Little is known about the source of referrals for non-specialist palliative care services, as no studies were found investigating this.

There is a gap in the literature identified here, as understanding why patients are referred to specialist and generalist palliative care services, and who refers them appear under-researched.
<table>
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<tr>
<th>Author, Country</th>
<th>Date, theme</th>
<th>Research question/theme</th>
<th>Research approach</th>
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<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
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<tbody>
<tr>
<td>Groot et al. (2005b) Netherlands</td>
<td>To investigate the extent to which professionals requested assistance from palliative care consultation teams</td>
<td>Prospective study of consultations with 21 teams, collecting routine registration data over a 2 year period</td>
<td>4351 consultation requests recorded by teams</td>
<td>54% of requests from GP, 10% other doctor, 9% district nurse, 16% hospital nurse, 8% other. 42% referrals for physical problems, 7% psychological, 3% social, 1% spiritual, 12% pharmacological, 13% care organisation</td>
<td>26 Appears to be an update of the Kuin (2004) study below. No disaggregation of data from teams working in hospital or community settings</td>
<td></td>
</tr>
<tr>
<td>Bestall et al. (2004) UK</td>
<td>To assess current views of access and referral to specialist palliative care</td>
<td>Qualitative semi-structured interviews to explore the views of patients and professionals</td>
<td>12 health and social care professionals, 3 GPs, 6 community nurses and 13 patients. Identified in specified localities by snowball technique</td>
<td>Patients and professionals described main reasons for referral to specialist palliative care as common symptoms and triggers (pain, nausea, psychological needs, fear). 'Complex' patients referred with more than one need, or where unable to cope.</td>
<td>24 Reporting impressions of referral reasons, rather than reasons given for specific patients</td>
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<td>Author, Date, Country</td>
<td>Research question/theme</td>
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<td>Fellowes et al. (2003) UK</td>
<td>Perceptions of district nurses towards referrals to Marie Curie Nursing Service</td>
<td>Questionnaire, based on conditions / prognosis of patient prompting referral</td>
<td>879 district nurses of 1379 (64% response)</td>
<td>High likelihood of referral for 88% of DNs for factors impacting on family or carers, 62% practical problems, 64% psychological problems, 59% social problems, 57% other physical problems, 57% other physical problems, 34% communication problems, 42% pain</td>
<td>21 Difficult to appraise utility of study with no definition of ‘incurable’, palliative or terminal given – or apparently indicated to respondents. Referrals are to Marie Curie, a very specific form of care</td>
<td></td>
</tr>
<tr>
<td>Kuin et al. (2004) Netherlands</td>
<td>To investigate the work of palliative care consultation teams</td>
<td>Prospective study of consultations with 19 teams, collecting routine registration data, and mailed questionnaire to referrer over a 1 year period</td>
<td>2040 registered consultations</td>
<td>66% requests from doctors (52% GP, 11% specialist, 2% nursing home), 22% from nurses (9% hospital, 7% district, 2% hospice), 11% others. 61% of referrals from primary care. Problem categories: 77% physical problems, 35% organisation of care, 34% pharmacology, 32% psychological problems, 18% support, 16% carer</td>
<td>26 Data related to needs of individual patients, but little details of context of teams</td>
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<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>Skilbeck et al. (2002) UK</td>
<td>To describe the work undertaken by Macmillan nurses in two regions in the UK</td>
<td>Comparative case studies of different hospital and community Macmillan teams (demographic data, interviews, diaries, records etc.)</td>
<td>Prospective data on new referrals (814) to 12 teams of Macmillan Nurses</td>
<td>issues, 15% social problems, 8% spiritual. Pain most common physical problem 32% referrals from hospital nurses, 28% hospital doctors, 13% GPs or DNs, 8% out patient clinics, 3% self or family referral 57% referred for emotional care, 33% symptom control, 27% pain control, 18% discharge planning, 12% advice and information. (for just community 43% pain control, 67% emotional reasons)</td>
<td>27 Comprehensive analysis of the workload and work patterns of a number of Macmillan nursing teams Little disaggregation for referrals of hospital and community teams</td>
<td></td>
</tr>
<tr>
<td>Low et al. (2001) Australia</td>
<td>To assess GPs’ experience with a palliative care support service</td>
<td>Exploratory mailed questionnaire</td>
<td>63 (of 91) GPs in Eastern Sydney</td>
<td>Main reasons for referring patients pain control (73%), request for respite care (65%), assistance with terminal care (65%), control of other symptoms (41%),</td>
<td>24 Exploratory small scale survey, with no detailed information on sample or questionnaire administered. Data is on broad reasons for</td>
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<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>Bennett et al. (2000) UK</td>
<td>To audit referrals to all Leeds providers of specialist palliative care services</td>
<td>Prospective referral audit</td>
<td>130 referrals received</td>
<td>65% had physical symptoms that met eligibility criteria, 83% psychosocial, 57% both. 85% met criteria</td>
<td>Other (6%) referral, not related to actual patients</td>
<td></td>
</tr>
<tr>
<td>Costantini et al. (1999) Italy</td>
<td>To develop a staging system for terminal cancer patients, validated against survival</td>
<td>Multicentre (58) prospective study of a random sample of admissions to palliative care units (Mostly home or mixed hosp/home units)</td>
<td>601 patients of 3901 registered patients (22%) referred over 6 months in 1995</td>
<td>31% of referrals from GP, 13% oncologist, 29% other specialists, 14% relatives, 12% others</td>
<td>27 Appropriate method, although extending recruitment period may have resulted in better data. No data on need</td>
<td></td>
</tr>
<tr>
<td>Kite et al. (1999) UK</td>
<td>To identify the pattern of non-cancer referrals to a specialist palliative care service</td>
<td>Retrospective review of routinely collected data to in-patient, hospice and home care teams</td>
<td>196 referrals to home care arm (9% or 18 non-cancer)</td>
<td>11 patients referred by GP/DN, 5 hospital wards, 1 outpatient and 1 physiotherapist. 75% referred for symptom control, 38% for pain control, 31% terminal care, 19% emotional support, 13% future care planning, 13% hospice admission</td>
<td>21 Number of patients in home care arm of study too small to make any meaningful conclusions</td>
<td></td>
</tr>
<tr>
<td>Eve et al.</td>
<td>To survey specialist palliative care services</td>
<td>Questionnaire survey to all known providers</td>
<td>Data from 149 (75%) in patient units, 235</td>
<td>54% of referrals from GPs and 32% from</td>
<td>21</td>
<td></td>
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<tr>
<td>Author, Country</td>
<td>Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>(1997) UK</td>
<td></td>
<td>about their provision during 1994/5</td>
<td>in the UK</td>
<td>(68%) home care services, 168 (81% day care units)</td>
<td>hospitals for home care services. No reason for referral data presented for home care services</td>
<td></td>
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<tr>
<td>Nash (1993) UK</td>
<td></td>
<td>To examine referral patterns to one Macmillan nursing team.</td>
<td>Referral checklist used</td>
<td>Data from 496 referrals to the service between 1989 – 1990, of which 431 had stated reasons for referral</td>
<td>68% referrals for ‘support’, 19% for symptom management, 10% counselling, 3% to access services, 13% no reason stated. In one month (54 referrals), 64% from GPs, 11% from DNs, 9% hosp doctors, 9% hosp nurses</td>
<td>19 Few details given of data collection or analysis procedures, and information based on few referrals</td>
</tr>
<tr>
<td>Dunphy and Amesbury (1990) UK</td>
<td>To identify characteristics which may distinguish between home care and inpatient hospice patients</td>
<td>Retrospective review of patients using routinely collected data</td>
<td>404 in-patient hospice patients and 143 home care patients who either died or were discharged from one hospice in 6 months in 1988</td>
<td>29% of referrals to home care from hospital, 57% from GPs, and 41% from ‘other’</td>
<td>23 Little description of data analysis procedures</td>
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<tr>
<td>McCarthy (1990) UK</td>
<td>Study to develop a recording instrument and database to describe the characteristics of</td>
<td>Standard recording form regarding patients within 12 hospice services</td>
<td>Records completed on 195 patients</td>
<td>54% referred by GP, 37% by hospital staff, 8% by community nurses.</td>
<td>21 Patients referred for both in-patient and home care, no disaggregation of data</td>
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<tr>
<td>Author, Country</td>
<td>Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
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<tr>
<td>Evans and McCarthy (1984) UK</td>
<td></td>
<td>Information about the workings of a terminal care support team (home and hospital)</td>
<td>Retrospective record review of referred patients compared to death certification records</td>
<td>125 referred patients who lived within the district compared to 437 cancer deaths overall</td>
<td>77% for symptom control, 60% emotional support.</td>
<td>21</td>
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</table>
2.3.5 What factors act as barriers to or facilitate referrals from professionals to community palliative care services?

The studies reviewed in this section address factors which could affect the referral processes between professionals. McGorty and Bornstein (2003) in a selective literature review identify three main sources of referral barriers: professional factors; organisational factors; and patient factors, and these are used to structure this review. These studies are summarised in table 2.8.

2.3.5.1 Professional factors affecting referrals

Many of the studies identifying professional factors affecting referrals specifically investigate the influence of doctors on referrals. This focus appears primarily in US studies, where the role of the doctor in determining hospice admission appears pre-eminent (McGorty and Bornstein, 2003). This section integrates research both on doctors and other professionals, indicating the focus of the studies.

Knowledge and skills

Professionals’ knowledge and skills can affect their referrals to community palliative care services in a number of ways. Identification of a lack of knowledge or skills to deal with particular patient situations may trigger referrals. A recent small study in the UK investigating district nurses’ identification of triggers for referral to Macmillan nurses found that referrals are made when nurses identify their own time or skill deficits (Aitken, 2006). Such triggers are rarely reported in the reviewed studies however, with lack of knowledge about palliative care services and what they could offer more likely to be discussed.

A multi-professional study by Bestall et al. (2004) in the UK found professionals interviewed identify that both a lack of general practitioner knowledge about care, and a lack of knowledge about what can be achieved in specialist care act as barriers to referrals. This study resonates with the findings of US studies of referring doctors where for example self rated competency in knowledge about hospice care is significantly positively associated with referral practices (Bradley et al., 2002). Simply being aware of the existence of services does not guarantee
referrals, as a UK study found that nearly all the general practitioners and district nurses surveyed were aware of local specialist palliative care services, but 6 – 7% of them still never referred (McKenna et al., 1999). This reluctance to discuss services or refer patients is echoed in two earlier US studies. In one, 90% of doctors claim to be aware of hospice services, but only half of them actually discussed hospice with patients who may benefit from it (Gochman and Bonham, 1988). In the other only 24% of doctors were aware of hospice services because they had previously referred patients (McNeilly and Hillary, 1997).

Receiving training in palliative care also appears to influence referral patterns. Doctors who receive more training feel that this enables referrals (Friedman et al., 2002), whilst a study of home health nurses who appear mostly resistant to hospice referral found that 52% had never received education in palliative care (Schim et al., 2000). A paucity of education in palliative care emerges in some studies investigating referral barriers with studies reporting 28% of doctors having no training in ethics or care of the dying (Hanson et al., 1999), or doctors reporting they felt they received inadequate training (Miller et al., 1997). It may be that palliative care education could enable referrals. Whilst there are studies investigating education in palliative care (e.g. Barclay et al., 1997; Charlton et al., 2000; Barclay et al., 2003; Hughes et al., 2006; Low et al., 2006), none examine the impact of education on referral practices rather than knowledge acquisition or practice competence. Knowledge or education are barriers to referrals which could be addressed, and therefore warrant further investigation, particularly as broader research regarding general practitioner referrals to hospital specialists indicates that educational initiatives may have an impact on referral practices (Faulkner et al., 2003; Grimshaw et al., 2005). A recent literature review concluded that there is overwhelming evidence of a general lack of knowledge and education about palliative and hospice care, and the authors argue that educational strategies are required to address this (Ahmed et al., 2004).

Knowledge about palliative care and knowledge of palliative care services appear to have some relationship to referral. However, whilst being aware of a service may be a necessary pre-requisite for referral, it appears insufficient as an explanation for many referrals.
Prognostication

The difficulties of prognostication in palliative care are well known (Glare et al., 2003), and the relationship to timing of referrals noted. Here, professionals' interpretation of the impact of prognostication difficulties is reviewed. In one study of US doctors, difficulties in prognostication are identified as the most likely referral barrier (59% of responses) (Weggel, 1999). Such difficulties are not only noted by doctors, as a study reporting the views of family members about referral identifies that 15% of them report physicians’ accuracy of prognosis as a barrier to early referral (Schockett et al., 2005).

Studies indicate that professionals may be deliberately delaying the discussion of hospice or palliative care services until a late stage in the patient’s illness. McNeilly and Hillary (1997) found that 28% of doctors do not consider it appropriate to discuss hospice services with patients until ‘it becomes clear that no other therapy will be effective, and it is obvious that the patient is entering a deteriorating state’, and a further 24% not referring until ‘after the illness has been diagnosed as terminal’. Whilst such definitions are open to interpretation, it appears that substantial numbers wait until a late stage in illness before discussing hospice care. Whilst this may reflect difficulties in prognostication, it could be related to an unwillingness to make early referrals, or to delay discussing a known palliative prognosis with patients.

Personal feelings about palliative care

Studies seeking to discover the attitudes of potential referrers towards hospice care frequently find positive responses. Oncology social workers have ‘overwhelmingly positive’ attitudes towards hospice philosophy of care (Becker, 2004). However, some caution must be taken in interpreting this, as the attitudinal ‘hospice philosophy and care scale’ contains items such as ‘Death is a normal part of living’, and ‘An interdisciplinary team is best’ which could potentially be interpreted as part of an individual’s philosophy of care. Only two of the ten items on the scale specifically mention hospice. These favourable attitudes are contrasted by Becker (2004) to the reality of referrals, where only 49% of patients are referred to hospice, despite such positive attitudes. This discrepancy may be
related to the non-specificity of the scale towards hospice, and hospice attitudes towards hospice referrals. Similar positive attitudes towards hospice are also identified by Ogle et al. (2003). All of the positive attitudinal items on their scale (9 of 13 items) are endorsed by at least 80% of doctors responding. These include hospice specific statements such as ‘I am comfortable discussing a hospice referral with patients and families’ (99% agreement), and ‘The physician is the most appropriate person to introduce the concept of hospice to patients and families’ (81% agreement). An earlier study also found that doctors are comfortable with hospice care, disagreeing strongly with statements indicating that referral to hospice means failure (Miller et al., 1997).

These positive attitudes towards hospice care per se can be contrasted with research regarding the specifics of referral which tends to identify discomfort with elements of palliative care provision. The perceptions of hospice ‘experts’ across the US are that there are significant barriers to hospice referral because doctors have difficulty accepting death and moving away from curative treatments. They also feel that doctors felt they were giving up on patients when a hospice referral is made (Friedman et al., 2002). The negative connotations of hospice and the difficulties of negotiating hospice care with patients are also identified by other studies. For example, in one study of doctors in the US, 16% of them found it difficult to tell patients about terminal diagnoses, 2% felt it was professional defeat to suggest hospice, and 6% were uncomfortable talking about death and dying issues (Weggel, 1999). This is reiterated by McNeilly and Hillary (1997) who found that 17% of doctors found a hospice discussion with patients uncomfortable, and by Johnson and Slaninka (1999) who found that family members feel that doctors refusal to disclose terminality is a barrier to referral, although 60% of the doctors studied did not perceive this as a barrier. These issues may relate to the difficulties in prognostication, and delays in referral reported earlier.

**Personal feelings about own role in palliative care**

The way professionals perceive their own role, and the role of the services they work within, could have an effect on decisions to refer patients to specialist palliative care services. Some studies look at the perceptions of those providing
‘general’ palliative care services such as nursing homes, district nurses and general practitioners. Most recently, a US study found that nursing home administrators are much less likely than hospice administrators to believe that hospice improves quality of care, and more likely to feel that the nursing home provides a good standard of care without using hospice (Hanson et al., 2005).

This belief in a generalist service providing good care without referral to specialist palliative care services is also found in other studies, briefly summarised here. District nurses feel they are able to provide good palliative care themselves (Fellowes et al., 2003), and see themselves as main community care providers to cancer patients (McHugh et al., 2003). General Practitioners and District nurses do not refer to a hospital at home service because other support is sufficient (37% DN, 46% GP) (Todd et al., 2002). Home health care nurses feel their care and hospice care are similar, and resist hospice referral as long as services could be provided by home care (Schim et al., 2000). Thirty seven percent of non referrers (GPs and DNs) do not refer to a specialist palliative care service because patients already have good support from the primary health care team (McKenna et al., 1999). General practitioners believe they have an important role in providing palliative care (Pugh, 1996), 13% of general practitioners feel that the primary health care team should be the sole provider of palliative care (Seamark et al., 1993). General practitioners belief that the primary health care team could manage patients is a barrier to referral to a specialist home care team (Boyd, 1995).

Attitudinal barriers amongst non-specialist providers of care such as those reported above could be a significant factor in affecting referral practices, but are significantly under researched in comparison to the multitude of studies investigating the different characteristics of referred patients explored earlier. These studies highlight the importance of not just studying the presence of different utilisation patterns, but the possible reasons behind them. It may be that the personal beliefs of referring professionals about services and patients’ needs are significant influences on referral.

What is also noticeable about these studies is that most were carried out in the UK in contrast to, for example the studies reviewed in the section on ‘personal feelings about palliative care’ where all came from the US. It is not clear whether this is
coincidental, a reflection of the different ways palliative and community care are provided in the UK and US, or an indication of different research interests in the two countries. The fact that two US studies report similar data to the UK studies may indicate that these are issues of concern in all countries.

2.3.5.2 Organisational factors affecting referrals

Organisational differences in palliative care provision between different countries affect the type of factor included in research studies. In the US the dominance of the Medicare hospice benefit on the sector cannot be ignored, and many of the organisational factors reported are related to the particular demands made because of this benefit. For example, 63% of hospices surveyed in California restrict access to hospice on at least one Medicare related criterion (lacking a caregiver 26%, unwilling to forego hospitalisation 29%, receiving complex medical care 38%, receiving radiotherapy 36%, receiving chemotherapy 48%) (Lorenz et al., 2004). Whilst the format only allowed yes or no answers which may not represent the subtlety of decision making processes, this still represents significant organisational barriers largely unknown to those providing similar care in the UK. Such barriers are also found in other studies, with one study finding 13% of referrals refused by hospice (patient unfunded, unsafe home, no caregiver, receiving active treatment) (Sanders et al., 2004), and lack of hospice funding being a barrier identified by an expert panel (Friedman et al., 2002).

However, although different, organisational barriers are still reported in some UK studies. These include a confusing lack of common referral criteria to specialist palliative care services within the same area, and barriers caused by requests for medical referrals rather than from other professionals (Payne et al., 2002), and service constraints such as a perception of lack of availability of places being the most common reason for not referring a patient who may be suitable for a hospital at home service (63% DNs, 62% GPs) (Todd et al., 2002).

It is unknown whether the paucity of studies in the UK investigating organisational barriers to referrals reflects a perception that organisational barriers are unlikely to be important, or a failure to realise that such barriers may exist. Whilst there are very different barriers in the USA, the existence of a Medicare policy that
effectively restricts referrals to certain individuals does appear to have an impact on access research. For example the Medicare requirement that there be a home carer is clearly reflected in the increased referrals of those who have such support. It may be that similar organisational, structural or policy related issues also affect referral patterns in the UK in unknown ways, and this merits further investigation.

2.3.5.3 Patient factors affecting referrals

This section reviews research reporting health care professionals’ views on patient and carer related barriers to referral. Research about patients’ own views on referral is addressed in the next section of this review.

Professionals perceive significant family and patient barriers to referral to palliative care services because referral means patients confronting the terminal nature of their illness and fears of dying. So, district nurses feel that patients can be fearful of a referral to a Macmillan nurse because of perceptions about what she is and does (Aitken, 2006). Similar reluctance to hospice referral is reported by Becker (2004), where 77% of social workers report resistance to hospice from patients or families – often because of denial of need by family (39%) and patient unwillingness to end active treatment (29%).

Other studies reporting similar findings include: the refusal of care because of a desire for curative treatment, or in denial (Bestall et al., 2004); patients or family refusing referral (Sanders et al., 2004); patient barriers reported as the need to confront end of life issues, that it means giving up, and negative connotations of hospice. (Friedman et al., 2002); that patients were not referred to a hospital at home service because of patient and carer reluctance (reported by 30% DNs, 10% GPs) (Todd et al., 2002); because family conflict about best care is a major barrier to good care (72% physicians reporting) (Kayashima and Braun, 2001); that families from black and ethnic minority backgrounds prefer to provide their own care and are often unaware of hospice, (Karim et al., 2000); that inaccurate perceptions of hospice are held by patient and carers, and that patients refuse to acknowledge dying (Johnson and Slaninka, 1999); that 16% of non referring district nurses and general practitioners do not refer because of patients negative
perceptions of hospice nurses (McKenna et al., 1999); that doctors agreed most with the barrier statements that the patient hasn’t accepted terminal diagnosis, that patient desires to continue life prolonging treatment, or that there are no family or friends to help provide care (Weggel, 1999); and more positively patients who acknowledge terminal status and whose informal carers know about hospice have a high probability of referral (Prigerson, 1991).

It is important to reiterate that all of these research studies draw their data from surveying or interviewing health care professionals, not from patients or carers. What is reported is the health care professionals’ perceptions of barriers, not necessarily what patients and carers may think and believe. However, these barriers may present a very real obstacle to palliative care referral. If a professional both believes that patients and carers have negative perceptions about referral to palliative care services, and is additionally reluctant to discuss prognosis or hospice care, then these two factors could substantially affect the number of patients accessing palliative care services.

In summary then a number of factors which are likely to affect referral to and use of palliative care services have been identified. Palliative care is most likely to be discussed and chosen when patients (and their informal carers) are believed to acknowledge their impending death, when patients meet requirements for admission, when doctors and other referrers understand and accept what palliative care has to offer and when doctors and other referrers perceive there are benefits to referral to other services above the care they could offer themselves (McGorty and Bornstein, 2003).

A criticism of this body of research is its particular reliance on one research method, the survey approach. Of the 37 studies reviewed in this section (table 2.8), 26 are based on questionnaire data. Whilst this is potentially a very appropriate way to gather data from large numbers of professionals regarding referral practices, its use pre-supposes that the survey questions capture the appropriate dimensions of the research topic. However, two of the studies (Weggel, 1999; Becker, 2004) also report additional data to the survey data, either because the survey findings appear contradictory (that those with a positive attitude to hospice still did not refer) (Becker, 2004), or that supplementary
interview data revealed barriers not elicited from the survey (Weggel 1999). Whilst these may be atypical, these reports raise concerns that there are potentially unexplored areas. There is no research looking in depth at factors influencing professionals’ decisions to refer to palliative care services, using exploratory methods which do not pre-suppose which issues may be important to research.

As previously discussed, this is also an issue in non-palliative care research, highlighted in reviews of research into general practitioner referrals to hospital services, where the reliance on the survey method to the detriment of more in-depth explanatory work has hampered understanding of the influences on such referrals (Wilkin and Smith, 1987; King et al., 1994; O’Donnell, 2000). The few studies exploring this field suggest four groups of influencing factors: GP-associated factors (such as personality, knowledge, relationships with patients); patient-associated factors (such as socio-demographic characteristics, expectations, preferences); case-specific factors (such as type of condition); and structural factors (such as waiting lists, practice organisation, proximity to hospital) (O’Donnell, 2000). There appears to be some concordance between these factors and the patient, organisational and professional factors discussed here. It may be that these are worthwhile avenues for further research.
Table 2.8  Studies investigating what factors act as barriers to or facilitate referrals from professionals to community palliative care services

<table>
<thead>
<tr>
<th>Author, Date, Country</th>
<th>Research question/theme</th>
<th>Research approach</th>
<th>Participants</th>
<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
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<tbody>
<tr>
<td>Aitken (2006) UK</td>
<td>To identify triggers which motivate DNs to refer patients to Macmillan nurses</td>
<td>Qualitative, exploratory interviews with volunteer sample working with author</td>
<td>8 DNs</td>
<td>Three themes: <strong>Knowledge and skills</strong>: referred when DNs identified own skill or time deficits. <strong>Interprofessional</strong>: variability in referral and working practices. <strong>Perceptions of Macmillan</strong>: Patients can be fearful of referral</td>
<td>18 Very small scale study only of nurses referring to author, with no exploration of bias this could introduce</td>
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<tr>
<td>Hanson et al. (2005) US</td>
<td>To describe facilitators and barriers to hospice in nursing homes</td>
<td>Mailed questionnaire to nursing home and hospice administrators in North Carolina</td>
<td>241 (62%) nursing home administrators and 74 (85%) hospice administrators</td>
<td>83% nursing homes had a hospice contract. NH administrators less likely to believe that hospice improves quality of care, and more likely to feel that NH provides good care without using hospice</td>
<td>25 No information about what enrolling in hospice care when in NH actually entails</td>
</tr>
<tr>
<td>Schockett et al. (2005)</td>
<td>1) Family members assessment of timing of referral to home</td>
<td>Survey (telephone or mail)</td>
<td>237 of 416 (64% response telephone, 50% mail) family</td>
<td>47% of family members reported a physician centred</td>
<td>25 Method limitations: a proxy view, possible</td>
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<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
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<tr>
<td>US</td>
<td>hospice 2) Family members assessment of reasons for late referral to home hospice</td>
<td>Mailed questionnaire to random sample of Association of Oncology Social Workers membership. Used Hospice Philosophy Scale. Follow up survey to explore main findings</td>
<td>members of home hospice patients from two services who had died in the last 3-6 months</td>
<td>barrier to early referral, 15% noted physicians' accuracy of prognosis. 28% reported patient or family beliefs about hospice as a barrier to earlier referral</td>
<td>non response bias due to pre-selection of sample, small sample size</td>
</tr>
<tr>
<td>Becker (2004) US</td>
<td>To determine the attitudes of oncology social workers to hospice care and the frequency they made referrals</td>
<td>Mailed questionnaire to random sample of Association of Oncology Social Workers membership. Used Hospice Philosophy Scale. Follow up survey to explore main findings</td>
<td>424 (from 1000, 42% response). Follow up survey 64 (from 200)</td>
<td>62% employed in hospitals. 66% reported extremely or quite supportive doctors re: hospice. 77% reported resistance to hospice from patients, or families (74%). Mean percentage of all terminally ill patients referred to hospice was 49%. Overwhelmingly positive attitudes toward hospice from social workers. Reasons for discrepancy between low referral and good attitude: denial by family (39%), accepted hospice treatment (23%); recognised limitations of questionnaire approach in determining referral reasons, and initiated second survey</td>
<td>23 Recognised limitations of questionnaire approach in determining referral reasons, and initiated second survey</td>
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<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
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<tr>
<td>Bestall <em>et al.</em> (2004) UK</td>
<td>To assess current views of access and referral to specialist palliative care</td>
<td>Qualitative semi-structured interviews to explore the views of patients and professionals</td>
<td>12 health and social care professionals, 3 GPs, 6 community nurses and 13 patients. Identified in specified localities by snowball technique</td>
<td>unwilling to end active treatment (29%)</td>
<td>24 Superficial description of timeliness data</td>
</tr>
<tr>
<td>Lorenz <em>et al.</em> (2004) US</td>
<td>To evaluate selected hospice admission practices that could represent barriers to hospice use</td>
<td>Faxed or telephoned questionnaires to hospices within California</td>
<td>100 hospices (67% response rate)</td>
<td>Reasons for not referring: no register, so do not know patient, lack of GP knowledge about care, lack of knowledge about what can be achieved in specialist care. Patients can refuse care – cure not care, denial</td>
<td>27 Only yes/no question answers, which may not represent subtlety of actual decision making processes. Highlights potential differences in US hospices</td>
</tr>
<tr>
<td>Sanders <em>et al.</em> (2004)</td>
<td>To determine why referrals to hospice are made when they are</td>
<td>Mailed questionnaire to referring and non referring physicians in one area</td>
<td>328 of 699 physicians (47%), 240 referrers, and 88 non referrers</td>
<td>Refer about 60% of their terminally ill patients to hospice, and were 5% of their</td>
<td>21 Physicians responded included, but not exclusively, primary</td>
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<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
<td>Appraisal of study and quality score</td>
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<tr>
<td>US</td>
<td></td>
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<td></td>
<td>workload. Reasons for non-referral: refusal of family/patient, family wanting to care, hospital admission. 13% of referrals refused by hospice (unfunded, life expectancy, unsafe home, no care giver, active treatment). Younger female doctors more likely to refer, younger male GPs less likely</td>
<td>care physicians. No definition of hospice care given. Referrers drawn from only one hospice, not all</td>
</tr>
<tr>
<td>Fellowes <em>et al.</em> (2003) UK</td>
<td>Perceptions of district nurses towards referrals to Marie Curie Nursing Service</td>
<td>Questionnaire, based on conditions / prognosis of patient prompting referral</td>
<td>879 district nurses of 1379 (64% response)</td>
<td>Reasons for not referring included: DN able to provide good palliative care themselves, no MC nurse available, non cancer diagnosis</td>
<td>21 Difficult to appraise utility of study with no definition of ‘incurable’, palliative or terminal given – or apparently indicated to respondents</td>
</tr>
<tr>
<td>McHugh <em>et al.</em> (2003) UK</td>
<td>To examine the process of referral of cancer patients to DNs across primary and secondary care</td>
<td>Informal interviews with purposeful sample of DNs from three primary care trusts</td>
<td>20 district nurses (from 21)</td>
<td>DNs wanted all patients with cancer referred to build a relationship with patients. Some referral information</td>
<td>24 Small number of participants in only one area</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<tr>
<td><strong>Ogle et al. (2003)</strong></td>
<td>To examine the attitudes and knowledge towards hospice of primary care physicians</td>
<td>Questionnaire to all physicians referring to hospice care in the community in one area</td>
<td>190 of 264 physicians (72%). 131 were primary care</td>
<td>All of the positive attitudinal questions were endorsed by at least 80% of respondents. Strong agreement for hospice as a treatment option, and effectiveness. Comfortable with role facilitating referrals. Only 20% agreed with negative statements (including care take over). Some uncertainty over facts relating to hospice</td>
<td>21 No information given on the context of hospice care in the community surveyed</td>
</tr>
<tr>
<td><strong>Bradley et al. (2002)</strong></td>
<td>To examine the influence of self rated knowledge and attitudes on doctors referrals for hospice care</td>
<td>Cross sectional study using mailed questionnaires to doctors in Connecticut</td>
<td>231 physicians (52% response)</td>
<td>Most felt able to take care of terminally ill patients. Self rated knowledge and attitudes were significantly positively associated with referral practices</td>
<td>26 Sample included family physicians as well as other doctors. Hospice referral patterns may be subject to recall bias</td>
</tr>
<tr>
<td><strong>Friedman et al.</strong></td>
<td>To understand</td>
<td>In depth telephone</td>
<td>30 interviews with</td>
<td><strong>Referral enablers:</strong></td>
<td>23</td>
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</table>

- **Research question/theme**: The research questions and themes are focused on understanding the attitudes, knowledge, and referral practices of primary care physicians towards hospice care.
- **Research approach**: Various methods such as questionnaires, cross-sectional studies, and in-depth telephone interviews were used to collect data.
- **Participants**: The number of participants and their characteristics are provided for each study.
- **Findings/outcomes**: The findings typically include levels of agreement with positive and negative statements, as well as factors that enable referrals to hospice care.
- **Appraisal of study and quality score**: The quality of the studies is assessed and graded on a scale, with higher scores indicating better quality.
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<tr>
<th>Author, Date, Country</th>
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<th>Research approach</th>
<th>Participants</th>
<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
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<tbody>
<tr>
<td>(2002) US</td>
<td>attitudes and best practice around physician/hospice relationships with reference to referral making</td>
<td>interviews from semi-structured questionnaire with acknowledged hospice ‘experts’ across the US. Four site visits to hospices with ‘outstanding’ physician outreach.</td>
<td>experts and 4 site visits</td>
<td><strong>Physician:</strong> physicians who value collaborative approaches, who are better trained, good past experience with hospice, need to confront non-referrers. <strong>Patient:</strong> educate patients to request hospice, marketing, early outreach <strong>Hospice:</strong> relaxing regulations (i.e. prognosis). <strong>Barriers:</strong> <strong>Physician:</strong> Difficulty accepting death, cure vs. care, giving up on pts, opioid use. <strong>Patient:</strong> confronting end of life issues, giving up, negative connotations. <strong>Hospice:</strong> Funding barriers</td>
<td>Only the views of a particular sub set of those identified by others as providing good care</td>
</tr>
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</table>

<p>| Lamont and Christakis | To evaluate the possible role of physician factors in | Prospective cohort study of all patients admitted to 5 | 326 patients (76% completion rate) referred over 130 | Longer survival in hospice if physician had more experience | 25 Interesting data because it introduces |</p>
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<tr>
<td>(2002) US</td>
<td>survival of cancer patients receiving hospice palliative care</td>
<td>outpatient hospices using routine patient data and telephone survey of referring physician</td>
<td>days in 1996</td>
<td>of referring patients and estimated prognosis accurately. General internists and geriatricians referred earlier than oncologists.</td>
<td>the notion of physician factors in timing of referral. No information on type of service given. Arbitrary definition of accurate survival prediction</td>
</tr>
<tr>
<td>Payne et al. (2002)</td>
<td>To identify service providers and commissioners’ understanding of specialist palliative care</td>
<td>A formative evaluation framework using primarily face to face semi-structured interviews with providers or commissioners surrounding one palliative care centre</td>
<td>35 (92% response) of those initially invited, plus 9 additional interviewees suggested by participants</td>
<td>Reported confusing lack of common referral criteria to specialist palliative care, and barriers caused by the request for medical referrals. Much ambiguity in what is meant by palliative care between different people</td>
<td>26 Utility in exploring professionals’ opinions, not pre-determined questionnaire categories</td>
</tr>
<tr>
<td>Shipman et al. (2002)</td>
<td>To explore GP use of an attitudes towards specialist palliative care services</td>
<td>Semi-structured telephone interviews in inner city, urban and rural areas</td>
<td>63 GPs (51%) selected randomly from districts</td>
<td>84% currently providing palliative care. Used services for advice, information and updating. Models of use: seldom use (9), resource (25), extended team (5), handing over (7)</td>
<td>27 Interesting data on different patterns of use of services</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<tr>
<td>Todd et al. (2002) UK</td>
<td>To examine the views of health care professionals towards a hospice at home scheme</td>
<td>A survey of GPs and DNs whose patients were potential users of the hospice at home scheme 2½ years after scheme commencement</td>
<td>61 DNs (85% response) and 136 GPs (65% response)</td>
<td>49% of DNs and 30% GPs indicated they had not referred a patient who may be suitable for HAH: lack of availability of places most common reason (63% and 62%), but also rapid changes in circumstances (43%, 31%), other support sufficient (37%, 46%), pt/carer reluctance (30%, 10%)</td>
<td>25 Useful for providing data relating to generalists use of services. No data reported on the questionnaire itself or questions asked</td>
</tr>
<tr>
<td>Kayashima and Braun (2001) US</td>
<td>To assess physicians perspectives on barriers to good end of life care</td>
<td>Mailed questionnaire to all eligible physicians in Hawaii</td>
<td>367 physicians from 867</td>
<td>More recently qualified doctors may have referred more patients to hospice. Identified family conflict about best care as major barrier to good care (72%). 57% had received some training</td>
<td>23 Poor response rate, with no information on non-responders</td>
</tr>
<tr>
<td>Karim et al. (2000) UK</td>
<td>To examine the use of palliative care service by members of black/ethnic minority (BEM)</td>
<td>Retrospective analysis of referrals to one hospice in Birmingham, and interviews with</td>
<td>1681 referrals to hospice in 1996/7, 27 doctors (12 GPs from 24 and 15 hospital consultants</td>
<td>Four main themes from doctor interviews: <strong>Cultural traditions:</strong> BEM families prefer to</td>
<td>22 Most of the GPs who did not take part were of South Asian origin and this may have</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<tr>
<td>Schim et al. (2000) US</td>
<td>communities</td>
<td>doctors about referral practices</td>
<td>from 22)</td>
<td>provide own care. <strong>Meaning of hospice:</strong> BEM patients unaware of hospice. <strong>Information exchange:</strong> language barriers. <strong>Clinical issues:</strong> acknowledge expertise of the hospice, but some reluctance for fear of destroying hope</td>
<td>affected the results, explanation of sampling limited</td>
</tr>
<tr>
<td>Hanson et al. (1999)</td>
<td>To examine the frequency of life sustaining treatment use and describe</td>
<td>Telephone interview with family members of those 65+ who had died of cancer, 165 (69% response) physicians</td>
<td>461 (80% response) family members and 165 (69% response) physicians</td>
<td>28% of doctors had no training in ethics or care of dying, only 16% extensive</td>
<td>26 No discussion of what is meant by hospice. No rationale for the...</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<tr>
<td>US</td>
<td>what factors influence physicians treatment decisions</td>
<td>congestive heart failure, chronic lung disease, cirrhosis or stroke and their physicians. Identified from consecutive death certificates 1994 – 5.</td>
<td></td>
<td>educational experience. 85% said they were the primary care provider</td>
<td>choice of diagnoses</td>
</tr>
<tr>
<td>Johnson and Slaninka (1999) US</td>
<td>To identify and describe barriers to timely hospice access as perceived by caregivers, hospice staff, volunteers and doctors</td>
<td>Interviews with caregivers, and self-completed questionnaires with doctors who had previously referred, hospice staff and volunteers associated with one hospice</td>
<td>11 caregivers (from 96), 20 hospice staff (43% response), 22 volunteers (51%), 30 doctors (40% response)</td>
<td>Barriers: Knowledge deficit: inaccurate perceptions held by patients/carers, and reported by all. Acknowledging terminality: Patients refusal to acknowledge dying, and doctor reluctance to disclose (not seen as barrier by 60% doctors)</td>
<td>23 Only those associated with one hospice, and with low response rate.</td>
</tr>
<tr>
<td>McKenna et al. (1999) UK</td>
<td>To examine the perceptions of district nurses and GPs towards home hospice nurses</td>
<td>Postal questionnaires to district nurses and GPs</td>
<td>305 GPs (47% response) and 101 DNs (51% response)</td>
<td>Nearly all GPs and DNs are aware of palliative care services offered. 6% of GPs and 7% of DNs never refer: patients perceptions of hospice nurses</td>
<td>22 Description of study poor, and identification of responder and non responder differences absent</td>
</tr>
<tr>
<td>Author, Date, Country</td>
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<tr>
<td>Weggel (1999) US</td>
<td>To determine which barriers hinder or delay a physician’s decision to discuss hospice with patients.</td>
<td>Mailed questionnaire sent to physicians in one area of Wisconsin, and interviews with a selection of physicians</td>
<td>97 (of 147, 67%) physicians (primary care and specialists) and further interviews with 13 of participating physicians</td>
<td>Most agreement with: patient hasn’t accepted terminal diagnosis, patient desire to continue life-prolonging treatment, no family or friends to help hospice provide care, difficult prognostication. The more barriers cited, the less likely were referrals by that physician. Additional barriers revealed by interview: concern over loss of involvement, inconvenient, too late in illness, use home health instead</td>
<td>24 The additional barriers identified by interview indicate that the questionnaire may not have covered all the necessary domains</td>
</tr>
<tr>
<td>Daaleman and Frey (1998) US</td>
<td>To identify prevalence and patterns of physician referral to clergy</td>
<td>Postal questionnaires to Family Physician members of AAFP</td>
<td>438 family physicians (58% response)</td>
<td>80% reported referring to clergy and pastoral care providers, 75% choosing end of life</td>
<td>24 Identifying issues in a frequently overlooked area of referral in palliative care</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
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<tr>
<td>Lowden (1998) UK</td>
<td>Examines perceptions of health care professionals on when and how the decision to refer the patient to palliative care services is made</td>
<td>Questionnaires to hospital and community based staff.</td>
<td>Randomly selected GPs (21), community nurses (19) and hospital nurses (22) and doctors (18) within one health district. 67% response rate</td>
<td>Only 15% of GPs saw themselves as providers of palliative care, but only 8% of district nurses viewed GPs in this way. 22% of GPs saw DNs as providers, 15% of DNs described selves in this way</td>
<td>22 Description of conduct of study poor, and identification of type of service referred to non specific, but findings of interest in identifying differing attitudes towards referral timing</td>
</tr>
<tr>
<td>McNeilly and Hillary (1997) US</td>
<td>To understand the relationship between the timing of hospice information, the optimal point of entry to hospice, and the type of hospice information considered critical to hospice care</td>
<td>Mailed questionnaires to referring physicians, family of hospice users, family of home health users, hospice and home health staff – sampled from those affiliated with two area agency offices</td>
<td>46 physicians (24%), 19 hospice staff (100%), 51 home health staff (100%), 61 hospice family members (40%), 20 home health family members (47%)</td>
<td>17% of physicians found a hospice discussion with pts uncomfortable, and 41% felt pts appropriate for hospice care when accepted terminal illness. 71% reported they had discussed hospice services with pts, but only 2% had gone on to use</td>
<td>24 Low response rate from physicians</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
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<tr>
<td>Miller et al. (1997)</td>
<td>Do family physicians face issues regarding access to hospice programmes?</td>
<td>Mailed questionnaire to randomly selected members of AAFP, mainly Likert type responses</td>
<td>482 of 1104 (48%) family physicians</td>
<td>Concerns about access to hospice (partic. In-patient). Felt had inadequate training. Felt comfortable dealing with aspects of palliative care, but concerned about large opioid doses. Disagreed that referral to hospice meant lack of control. Disagreed that referred younger patients</td>
<td>25 Low response rate, but responders similar to non-responders. Strength from being a random, widely spread sample</td>
</tr>
<tr>
<td>Pugh (1996) UK</td>
<td>To elicit GPs reasons for referral to palliative care services</td>
<td>Cross-sectional interview study, using structured face to face or telephone interview with three groups of GPs: frequent, non and nurse referrers</td>
<td>45 GPs (51%) (15 in each group)</td>
<td>Frequent referrers referred for nursing support (40%), whilst non-referrers said would refer for pain control (53%). Did not refer if carers coping well. Believed selves to have an important</td>
<td>21 No appraisal of whether stratification of sample influenced overall balance of results</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
<td>Research approach</td>
<td>Participants</td>
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<tr>
<td>Turner (1996) UK</td>
<td>To evaluate direct access by GPs to specialist community palliative support</td>
<td>Telephone questionnaire to all GPs referring to service, and collection of clinical data regarding patients referred during 5 months</td>
<td>38 patients referred by 26 GPs for nursing assessment, 81 patients referred by 54 GPs for consultant assessment, 20 questionnaires (87%)</td>
<td>45% increase in overall referrals to the service – direct access nursing referrals additional to consultant referrals. 75% of nursing referrals for ‘nursing support’. GPs liked speed of access, flexibility, saving money, and better communication</td>
<td>18 Limited evaluation of one service initiative</td>
</tr>
<tr>
<td>Bebko (1995) US</td>
<td>To examine and compare gatekeeper knowledge of hospice and their evaluation of hospice</td>
<td>Mailed (Drs) or telephone (other professionals) questionnaire to convenience sample of physicians, nurses, social workers and clergy in one city</td>
<td>82 participants (37%), 27 nurses, 26 clergy, 15 physicians, 8 social workers and 6 unknown</td>
<td>No differences between the groups on knowledge of features of hospice except about Medicare benefit. Identified counselling and support as most familiar feature</td>
<td>20 Survey limited in scope, and with poor response</td>
</tr>
<tr>
<td>Boyd (1995) UK</td>
<td>To evaluate the contribution of specialist home care team from the perspective of GPs in South London</td>
<td>Mailed questionnaires to GPs in three adjacent FHSA areas of South London</td>
<td>560 GPs (79%)</td>
<td>96% had used at least one specialist service. 64% would refer all terminally ill patients. Barriers included patient</td>
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<tr>
<td>Berry et al. (1994) US</td>
<td>To develop a better understanding of the determinants of selection of final site of care (community hospice vs. hospital) for terminally ill patients with lung cancer</td>
<td>Retrospective study of lung cancer deaths in Clark County in 1986 using routine data from death certificates and the cancer registry</td>
<td>251 patients (from 328 deaths) in 1986</td>
<td>20 Data on characteristics is related to time of death, not time of referral</td>
<td>20</td>
</tr>
<tr>
<td>Seamark et al. (1993) UK</td>
<td>To examine the knowledge and perceptions of GPs and community nurses about a domiciliary hospice service</td>
<td>Mailed questionnaire to all GP principals and community RGNs in the study area</td>
<td>127 GPs (71%) and 58 nurses (79%)</td>
<td>59% of GPs (53% nurses) had access to domiciliary service and had used it. Nurses more aware of services provided. Difficulties reported in knowing who is responsible for patients (10% GPs, 32% nurses), 13% of GPs felt PHCT should be sole provider of care. Services generally welcomed</td>
<td>23</td>
</tr>
<tr>
<td>Prigerson (1991)</td>
<td>To examine factors expected to facilitate or inhibit the use of</td>
<td>Interviews with patients, physicians and informal carers.</td>
<td>76 critically ill patients and their professional and informal</td>
<td>Patients who acknowledge terminal status, whose doctors</td>
<td>23</td>
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<tr>
<td>Author, Date, Country</td>
<td>Research question/ theme</td>
<td>Research approach</td>
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<td>Findings/outcomes</td>
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<td>US</td>
<td>home-based hospice services</td>
<td></td>
<td>caregivers</td>
<td>disclose status, whose informal carers know about hospice have high probability of referral</td>
<td>unknown issues, but only conducted with elderly patients</td>
</tr>
<tr>
<td>Gochman and Bonham (1990) US</td>
<td>To examine social structural dimensions of discussions and decisions to enter hospice care</td>
<td>1) Interviews with caregivers, patients, physicians and other decision makers for hospice 2) Mailed questionnaire to survivors of cancer deaths</td>
<td>150 hospice cases</td>
<td>Discussion likely to be initiated by professional outside patient's household, number of participants in discussion small, caregiver likely to make decision</td>
<td>23 Only looks at those inside hospice care</td>
</tr>
<tr>
<td>Hyman and Bulkin (1990) US</td>
<td>To investigate factors considered by physicians when deciding to discuss hospice with patients</td>
<td>Semi-structured interviews with physicians who had referred patients to one hospice</td>
<td>17 physicians.</td>
<td>A proactive stance towards disclosure of terminal diagnosis and perception of hospice as dignified place for dying create opportunities to accomplish factors favourable to hospice referral</td>
<td>22 Small study, only looking at doctors referring to one hospice, so may be very context dependent</td>
</tr>
<tr>
<td>Gochman and Bonham (1988) US</td>
<td>To examine dimensions of physicians involvement in decision to enter hospice care</td>
<td>1) Mailed questionnaire to physicians to determine awareness of hospice and degree hospice</td>
<td>45% response.</td>
<td>90% aware of hospice, but only ½ discussed hospice. Support was the most important reason for recommending</td>
<td>Not appraised, only abstract available</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach discussed. 2) Interviews with physicians of hospice patients to determine reasons for recommending hospice care</td>
<td>Participants</td>
<td>Findings/outcomes hospice</td>
<td>Appraisal of study and quality score</td>
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2.3.6 What are patients’ and carers’ views on referral to community palliative care services?

The views of patients and their informal carers towards referral to palliative care services had not been as thoroughly investigated as other areas until recently. Of the 17 studies reviewed in this section, 11 have been published since 2003, hence the results of these studies had less impact on the design and conduct of this study. It is hard to judge why this area has suddenly received more attention; it may be a reflection of the need to understand why patient characteristics appear to affect referral, the increasing prominence within all literature of the views of patients and carers, or the increasing emphasis on patient choice in policy. An area which is more comprehensively investigated is patient and carer satisfaction with services received (Wilkinson et al., 1999; Aspinal et al., 2003). However such studies are not reviewed here unless they specifically address an issue relating to access, as satisfaction with received care is outside the scope of this review.

Four main influences on referral can be identified from the studies reviewed in table 2.9: patients’ perceptions regarding professional barriers; their own views on their diagnosis, treatment and prognosis; their desire to ask for help; and their awareness of the services available to them.

Patients’ and carers’ perceptions of professional barriers

In two studies, patients or carers commented on barriers to their referral to palliative care services created by health care professionals. In one US study investigating family members’ assessment of reasons for late referral to home hospice care, 47% of family members of those who had recently died report a doctor-related barrier to early referral to hospice, and 15% note problems because of inaccurate prognostication (Schockett et al., 2005). Bereaved caregivers also note similar issues, identifying problems with prognostication as an issue delaying access to hospice, as well as a propensity for doctors to focus on curative care (Wyatt et al., 2000). These issues echo those identified by professionals in the review of research investigating professional barriers and facilitators to referral.
It is possible that such factors are not identified in some studies because most identify the concerns of patients and caregivers, not bereaved caregivers. It could be that professional related factors are primarily realised or recognised as such following the death of the patient. However, this theme lends further depth to the research on professional barriers, as it identifies that such barriers are not only noted by health professionals, but recipients of services and their carers.

**Patient’s and carer’s views about their illness**

The perceptions of patients and carers about the illness, treatment options, and possible prognosis all appear to affect referral.

Casarett *et al.* (2006) found that patient’s treatment preferences can be a barrier to hospice enrolment in the US. Their prospective study of 203 patients with cancer, chronic heart failure and chronic obstructive pulmonary disease found that patients who do not want life sustaining treatment are more likely to enrol in hospice, but that few of the patients they studied had preferences regarding treatment that would make them eligible for hospice. This is supported by earlier work finding that a focus on curative care (Wyatt *et al.*, 2000), or a preference for life sustaining treatment (Reese *et al.*, 1999) are barriers to referral. There are issues about patient expectations, as non-malignant diseases in particular have few treatment options which could be termed curative. This barrier to hospice care is particularly found in US studies, where hospice eligibility criteria generally demand that patients forego other treatment such as chemotherapy, or parenteral nutrition, a restriction rarely found in the UK.

More commonly, and across countries, studies found that a significant barrier to referral is that patients need to accept that they are in the palliative phase of their illness, and that referral to a possibly feared service would be appropriate. For example, 28% of family members in one study report that patient or family beliefs about hospice are a barrier to early referral (Schockett *et al.*, 2005). Other studies found that patients need to accept impending death (Schulman-Green *et al.*, 2004), that lack of understanding of illness is a barrier to home care use (de Graaff and Francke, 2003), that there are negative connotations associated with referral to Macmillan nurses or specialist palliative care services (Seymour *et al.*, 2003;
Luker et al., 2003), and that denial of impending death is a barrier (Wyatt et al., 2000). It also appears that professional and lay caregivers can have an impact on these perceptions and hence use of services. Prigerson (1991) found that caregivers who have prior experience of death are more likely to care for patients who use hospice, and that doctors disclosure of terminal prognosis to patients has a significant positive effect on hospice use.

There may be issues about professional and lay determinations of palliative and terminal care. Many patients whose illnesses are essentially ‘palliative’ from diagnosis (for example motor neurone disease, or chronic obstructive pulmonary disease) appear unwilling to label themselves as such until experiencing symptoms indicating impending death, or the need for ‘terminal care’ (Oliver and Webb, 2000; Ganzini et al., 2002; Elkington et al., 2004; Hughes et al., 2005; Elkington et al., 2005). Sensitive communication of prognosis to both patients and caregivers, and explanation of what palliative care services could potentially offer before the terminal phase may positively affect palliative care service use. However, this may be unlikely when professional reluctance to initiate such discussions is accounted for.

**Patient and carer willingness to ask for help**

A pre-requisite to referral is patients’ or carers’ acceptance that they have needs that could be met by formal health care services, followed by a request for help to meet those needs. Patients and carers may be unable to recognise needs, or if they do, to ask for assistance. Exley et al. (2005) found in interviews with patient and lay carers that patients could be reluctant to ask for help, not wanting to ‘bother’ professionals, or feeling that they are failures because they cannot manage without assistance. Similar results are reported in a study of the last year of life of patients with COPD, where bereaved carers report that people did not necessarily seek help, take up offers of help, or perceive there was a health problem (Elkington et al., 2004). A synthesis of three studies of patients’ evaluations of specialist palliative care also concludes that patients prefer services to initiate contact (Seymour et al., 2003). This finding is supported in the data from interviews with patients and carers reported by Beaver et al. (2000) where
participants report liking knowing that professionals were available, and that they pre-scheduled visits.

The studies reporting patients’ and carers’ views on asking for help are all UK studies. It may be that there are particular cultural or contextual issues regarding patients and their relationships with health care services in the UK which are not found in other countries. It is the case that cultural differences in attitudes towards palliative care services have been anticipated in studies of attitudes to hospice use by Mexicans in the US (Gelfand et al., 2004), by Turks and Moroccans in the Netherlands (de Graaff and Francke, 2003) and by African Americans in the US (Reese et al., 1999). Whilst two of these were not comparative studies, the study by Reese et al. (1999) did find that African Americans perceived more barriers to hospice use than European Americans.

**Awareness of and understanding about palliative care services**

The final barrier which patients and carers appear to face when accessing palliative care services is that they are either unaware of services offered, or have a vague or incorrect perception of what services could offer.

An Australian study has investigated in depth what patients know about the health services they may access when they are in the palliative phase of their illness. They found variable knowledge about services; although core services such as community nurses are well known (88% of patients, 90% of carers), patients and carers are less aware of more specialist services such as palliative nursing (64% patients, 53% carers) (Burns et al., 2004). There are differences in knowledge with patients more aware of most services than carers, and patients in metropolitan areas, women, those with more education, and retired carers being more likely to know about services. This lack of knowledge about services is found in other studies; with a lack of knowledge about hospice care found in Mexican communities (Gelfand et al., 2004), and in African American communities (Reese et al., 1999) in the US. A lack of knowledge of services in particular populations may be a further explanation for different service utilisation patterns. Programmes designed to promote service awareness may therefore have an impact on service use.
However, even when patients and carers do know of services, they can report an understanding which does not meet the reality of what is offered, which could affect how they choose to use and access services. In the US, one study of Mexican attitudes to hospice found that many believe hospice to be an in-patient facility, rather than the home care service most offer (Gelfand et al., 2004). In the UK, studies have found that there is a lack of understanding of what a district nurse does, accentuating their physical care role without acknowledging any psychological or family care dimensions. In addition no differences were perceived between district and Macmillan nurses in some studies (Wilson et al., 2002; Luker et al., 2003). Other studies support these findings, identifying that patients and carers do not understand the role of the Macmillan nurse (Beaver et al., 2000), or have a limited conception of what to expect from a referral to a specialist palliative care service (Jarrett et al., 1999a). Jarrett et al. (1999a) found that patients had two expectations of referral to a palliative care service; ‘someone to talk to’ and ‘pain control’, and that these limited conceptions of the role limit both what referral could offer, and what patients would ask of services.

Patients’ optimistic views of their illness, reluctance to ask for help or initiate contact with services, and poor awareness of the existence and scope of palliative care services appear significant, yet under-researched, barriers to referral. It may be that particular patient populations are more likely to overcome such barriers, and this is a potential explanation for different service use patterns. However research exploring this has not yet been undertaken. In addition, this work does not appear to have had an impact on approaches to policy or practice such as patient education that could ameliorate such barriers.
Table 2.9  Studies investigating patients’ and carers’ views on referral to community palliative care services.

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<thead>
<tr>
<th>Author, Date, Country</th>
<th>Research question/theme</th>
<th>Research approach</th>
<th>Participants</th>
<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
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<tbody>
<tr>
<td>Casarett et al.</td>
<td>To determine whether patient preferences are a barrier to hospice enrolment</td>
<td>Prospective cohort study in 15 ambulatory primary care and speciality clinics and 3 general medicine in-patient units. Multiple interviews over a period of up to 24 months</td>
<td>203 patients with cancer (32%), CHF (38%) and COPD (30%)</td>
<td>Patients more likely to enrol in hospice when they said they did not want low burden treatment. Patients with cancer more likely to enrol in hospice over time. Patients who did not want life sustaining treatment more likely to enrol in hospice, but few had preferences regarding life sustaining treatment that would make them eligible for hospice</td>
<td>27 US context, where patients have to forego other treatment to enter hospice programmes. Small sample size in one area may limit generalisability</td>
</tr>
<tr>
<td>Catt et al. (2005)</td>
<td>To determine the relationship between age and attitudes to death and attitudes to palliative care</td>
<td>Questionnaire (delivered by interview) to older people (55 – 74 and 75+) randomly sampled from general practice lists (selected to be representative of social banding)</td>
<td>570 older people (72% response)</td>
<td>Knowledge of hospice and hospice care high in both groups. Attitudes to death and dying similar in both groups. Believed it was easier to die in old age, but not that this should mean the young had greater access to</td>
<td>26 Important addition to knowledge re: why older people are less likely to access palliative care services</td>
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<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
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<tr>
<td>Exley et al. (2005) UK</td>
<td>To investigate the needs of people who are dying in the community of both malignant and non-malignant disease</td>
<td>Qualitative semi-structured interviews with patient and lay carers who were dying (every 4 months). Focus groups with GPs, DNs, OTs and specialist palliative care nurses within two GP practices</td>
<td>50 interviews relating to 29 patients. 4 had no carer</td>
<td>Very positive about primary health care teams. No difference in access to GPs between cancer and cardio-respiratory patients. Patients often reluctant to ask for help. Patients and carers rarely spoke about DNs</td>
<td>25 No data on referrals to specialist palliative care although seen as part of PHCT in focus group. Small study in only two practices committed to palliative care</td>
</tr>
<tr>
<td>Schockett et al. (2005) US</td>
<td>1) Family members assessment of timing of referral to home hospice 2) Family members assessment of</td>
<td>Survey (telephone or mail)</td>
<td>237 of 416 (64% response telephone, 50% mail) family members of home hospice patients from two services</td>
<td>47% of family members reported a physician centred barrier to early referral, 15% noted physicians accuracy of prognosis.</td>
<td>25 Method limitations: a proxy view, possible non response bias due to pre-selection of sample, small</td>
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<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
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<td>Burns et al. (2004)</td>
<td>reasons for late referral to home hospice</td>
<td>To establish the prevalence of patients with advanced cancer and caregiver knowledge of information about health services</td>
<td>28% reported patient or family beliefs about hospice as a barrier to earlier referral</td>
<td>Matched sample of 129 patient-caregiver pairs where both completed baseline questionnaire, and 87 pairs completing follow up at week 12</td>
<td>23 Unknown whether drawing sample from a hospital may affect their knowledge of community services</td>
</tr>
<tr>
<td>Elkington et al. (2004)</td>
<td>To assess symptoms in last year of life in patients with COPD and assess patients access to and use of health services</td>
<td>Qualitative interviews with bereaved carers of patients who had died of COPD in the last 3 – 10 months</td>
<td>88% of patients (90% carers) aware of community nursing, and 64% (53%) palliative nursing. Patients more aware of services than carers. Patients in metropolitan areas, women, those with greater education, and retired carers more likely to know about services</td>
<td>25 Retrospective analysis with carers not patients so may not represent patients’ views</td>
<td></td>
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<tr>
<td>Gelfland et al.</td>
<td>To examine factors affecting the use of</td>
<td>Focus groups of Mexicans living in</td>
<td>Barriers: Felt there was no knowledge about</td>
<td>23 Findings very</td>
<td>23</td>
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<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
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<td>(2004) US</td>
<td>hospice services by Mexicans</td>
<td>Michigan and Arizona, stratified by age and length of residency in US. Recruited via advertisement and through residents groups</td>
<td>focus groups with Mexicans, and 2 (20 participants) focus groups with providers of services to Mexicans</td>
<td>hospice care in Mexican community; Many believed hospice was an in-patient facility, and this impeded its use; Fears about ethnic discrimination; possible costs; language barriers; need to not lose hope</td>
<td>culturally specific</td>
</tr>
<tr>
<td>Schulman-Green et al. (2004) US</td>
<td>To characterise common experiences of patients and caregivers as they enter hospice care, focusing on caregiver perceptions of barriers.</td>
<td>In depth interviews with a purposive sample of caregivers of those enrolling with a hospice in Connecticut.</td>
<td>12 caregivers</td>
<td>Three common transition themes: 1) Accepting impending death 2) Challenges in negotiating the healthcare system. 3) Changing patient-family dynamics</td>
<td>22 Unclear how themes may translate out of specific context in this small study</td>
</tr>
<tr>
<td>de Graaff and Francke (2003) Netherlands</td>
<td>To explore the experiences of relatives of elderly terminally ill Turks and Moroccans regarding Dutch professional home care and the barriers to the use of this care</td>
<td>Qualitative interviews with relatives of terminally ill or deceased patients. Recruited via care organisations and community/resident organisations and groups</td>
<td>19 relatives were interviewed (9 users and 10 non users of home care)</td>
<td>Groups of users: deliberate non users (prefer to care by selves); reluctant users (used if better informed), elective users (had enough information and accepted care). Some</td>
<td>23 Findings culturally specific</td>
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<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
<td>Participants</td>
<td>Findings/outcomes</td>
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<tr>
<td>Luker et al. (2003)</td>
<td>To identify patients’ and carers’ perceptions of the role of the district nurse before and after hospital discharge. To investigate the needs of people with cancer, and the role of the district nurse in meeting these</td>
<td>Qualitative conversational interviews with patients with cancer and their carers recruited before discharge from a regional cancer centre</td>
<td>26 pre-discharge interviews with patients (8 with carers) and 22 post discharge interviews (15 with carers)</td>
<td>Lack of clarity about what the DN role was, stereotyping her role in physical care. Many were surprised to receive a visit, and anticipated few after care needs. Macmillan nurse was associated with terminal care, and referrals caused concern because of language barriers. Access: generally referred by GPs. Barriers: lack of understanding of illness; family structure (availability of female relative, decision to use home care made by head of family; social pressure to provide care); social environment; formal information given.</td>
<td>26 Useful study of perceptions of referral to general palliative care services as well as specialists</td>
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<td>Wilson et al. (2002)</td>
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UK
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<th>Author, Date, Country</th>
<th>Research question/ theme</th>
<th>Research approach</th>
<th>Participants</th>
<th>Findings/outcomes</th>
<th>Appraisal of study and quality score</th>
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<tr>
<td>Seymour et al. (2003) UK</td>
<td>To conduct a synthesis of three evaluative studies of palliative care services to ascertain patients' reported expectations and experiences of specialist palliative care</td>
<td>Secondary qualitative data analysis on interview data</td>
<td>37 patients interviewed during three evaluations of specialist palliative care services</td>
<td>Patients were confused about the term palliative care, and concerned about its connotations. Attitudes had been influenced by family and friends. Very positive evaluation once within services. Preferred services to initiate contact</td>
<td>26 Synthesis of studies potentially demonstrates applicability beyond specific contexts</td>
</tr>
<tr>
<td>Keegan et al. (2001) Ireland</td>
<td>To investigate relatives’ retrospective accounts of aspect of health care in the last year of life</td>
<td>Semi-structured interview incorporating a critical incident technique.</td>
<td>155 interviews (57% response) from a stratified sample of those dying in hospital 1996 - 1997</td>
<td>Reported not being able to access services when needed (i.e. physio, OT, GP visits). Some access inappropriate – i.e. denied home care as not got cancer, got telephone advice instead of a visit</td>
<td>21 Sample biased towards those who had received hospital palliative care services, and based on hospital deaths</td>
</tr>
<tr>
<td>Beaver et al.</td>
<td>To provide insight into users perspectives of</td>
<td>Semi structured interviews with</td>
<td>15 terminally ill patients and their 10</td>
<td>Participants liked to know that</td>
<td>24 Participants not</td>
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<td>Author, Date, Country</td>
<td>Research question/theme</td>
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<tr>
<td>(2000) UK</td>
<td>palliative care service provision</td>
<td>terminally ill patients and their carers recruited through general practices</td>
<td>lay carers, 19 bereaved carers</td>
<td>professionals available, even if they were not regularly visiting, however some preferred scheduled visits so they could arrange to be there. Lack of understanding of role of Macmillan nurse</td>
<td>randomly selected, so high probability that those who were high service users (and therefore recalled by PHCT gatekeepers) were more likely to be recruited</td>
</tr>
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<td>Wyatt <em>et al.</em> (2000) US</td>
<td>What factors to bereaved care givers perceive as barriers to hospice access</td>
<td>Qualitative focus group discussion. Participants recruited via two hospice agencies in Michigan</td>
<td>12 bereaved care givers (from 40) (10 women, 2 men). A mean of 10 months since bereavement. Two focus groups, each group met twice</td>
<td>Two access themes (of six) Societal and health system issues delayed access. (Physician prognostication, denial of death, payment issues). Education needs of health professionals that affect access. (Poor communication, focus on curative care)</td>
<td>27 Used a small, self selected sample, which may introduce bias. Series of focus groups allowed participants to become familiar and talk more readily</td>
</tr>
<tr>
<td>Jarrett <em>et al.</em> (1999a)</td>
<td>To identify patients and relatives expectations and experiences following referral to a specialist palliative care service</td>
<td>Qualitative analysis of interviews from a larger prospective longitudinal study of 100 patients referred to a specialist</td>
<td>20 interviews (18 patients, 11 carers).</td>
<td>Two expectations of referral to a specialist palliative care service: ‘Someone to talk to’, and ‘pain control’. There was a limited</td>
<td>25 Only a study of those already accessing specialist palliative care services</td>
</tr>
<tr>
<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
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<td>UK</td>
<td></td>
<td>palliative care service</td>
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<td>conception of the role and therefore what referral could offer, a minority did not know what to expect of referral</td>
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<tr>
<td>Reece et al. (1999)</td>
<td>To understand conflicts between African American beliefs and hospice philosophy and how this affects hospice use.</td>
<td>Participatory action research project. This reports qualitative interviews with Christian African American Pastors and a questionnaire study with African Americans &amp; European Americans</td>
<td>6 interviews with Pastors and 127 questionnaires returned</td>
<td>Qualitative study: Cultural barriers: differences in values regarding medical care (not agree with care in the home, preference for life sustaining treatment, prefer not to plan for death, care by own not strangers). Institutional barriers: lack of knowledge of services; lack of insurance; lack of trust and lack of diversity in health care staff. Questionnaire: Greater degree of barriers in African American population</td>
<td>21 Possibly difficult to apply findings outside specific context, and few details of sample or method provided.</td>
</tr>
<tr>
<td>Prigerson (1991)</td>
<td>To examine factors expected to affect the use of home based</td>
<td>Questionnaires to physicians, primary care givers and 76 doctors (68% response) who then selected patients.</td>
<td>Caregivers who have a personal experience with death, or who</td>
<td>24 No description of the characteristics of the</td>
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<td>Author, Date, Country</td>
<td>Research question/theme</td>
<td>Research approach</td>
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<tr>
<td>US</td>
<td>hospice services</td>
<td>terminally ill patients (over 65) in California</td>
<td>89% response patients, 87% response carers</td>
<td>perceive patient consent to hospice care are more likely to care for patients who use hospice. Doctors disclosure of terminal prognosis positive effect on hospice use. Patients’ treatment preferences do not have a notable effect on treatment received, but their death acknowledgment does</td>
<td>patients sampled.</td>
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2.4 Summary of literature review

The evidence reviewed here indicates that a number of professional, organisational and patient related factors appear to have an impact on whether and when a patient is referred to community palliative care services.

This review is broad in scope, and identifies a number of key points which are summarised here.

- Referrals to palliative care services often appear tardy; consequently those accessing services are very ill. This may mean that patients are less able to benefit from services. Late referrals may be due to difficulties in prognostication.
- Not all patients in the palliative phase of their illness access palliative care services, nor does any service see every patient in an area.
- Patients with particular characteristics appear less likely to use palliative care services. Those who are older, male, from a minority ethnic population, who are not married, who do not have a carer at home, who live in deprived areas, and who do not have cancer are less likely to receive care from palliative care services. Identifying these different use patterns has been a major focus of research.
- Patients with explicit physical or psychosocial problems are more likely to be referred. Referrals may originate from within or outside community services.
- The knowledge, skills and attitudes of health care professionals affect referral practices. Professionals may not be aware of services, they find prognostication and discussing palliative care with patients difficult, and can believe that referral to specialist care may not be required. Professionals also perceive patients’ reluctance to be referred.
- Patients are aware of some of these professional barriers to referral, and also have referral concerns about being identified as being in the palliative phase of illness, and about proactively requesting referral. Patients have poor awareness and understanding of services.
There are particular issues emerging from these research areas and the methods used to address them.

Many of the studies investigate access issues in countries other than the UK. For example, many studies draw on US data, and service use in that country is affected by issues such as Medicare insurance rules, and the increased use of hospice by patients with non-malignant illnesses (Connor et al., 2004). There are different issues in different countries which could possibly affect the context in which access to services takes place. This potentially makes generalising from a study in a different country difficult, and so the evidence base upon which our understanding of UK referral patterns could be based is smaller than initially envisaged. Any comparisons are made more difficult by the lack of description of services studied or services potentially available to patients. The lack of contextual information for referral decision making practices is an issue which needs to be addressed in future research.

The emphasis on investigating which patients access palliative care services must also be questioned. One reason for the large evidence base may be the ability to study such patient characteristics using retrospective, routinely available data. Researchers continue to investigate this area, with similar studies, with similar findings, across different countries reviewed between 1984 and 2006. Indeed there has been a recent call for more research investigating utilisation patterns (Hagen et al., 2006). A related body of work investigating the association between similar patient characteristics and place of death, has recently been criticised for having no theoretical basis underlying the research questions, with no rationale for grouping or identifying the factors given (Gomes and Higginson, 2006). Such a criticism could also be levelled at this access work, with factors investigated often apparently chosen because of their presence on routine databases, rather than a predicted, theoretically driven rationale. Whilst it can be argued that all studies have a theoretical orientation by virtue of the way a research question is framed (Merriam, 1998), it is notable that little of the literature reviewed, in any section of the review, was explicitly theoretically driven, or related findings to extant theory. There is therefore little overt theoretical direction to the research reported here provided by the literature review.
What researchers have rarely done is move beyond such descriptive work to examine what is happening in the referral or other processes which may result in the observed referral and utilisation pattern. An early review of this work suggests that the retrospective review of routine data has been useful in allowing an understanding of the patterns of referral, and that researchers need to develop studies which investigate how and why these characteristics have an impact (Grande et al., 1998). Sadly this suggestion has been largely ignored, with little work published in this area. There is also the potential for this suggestion to be broadened, and for studies to be developed which investigate in depth referral processes, and what influences them.

It may be that apparent inequities in access are an artefact of the different needs of patients and/or carers, or their perceived ability to benefit from services. Reviewed studies appear to assume notions of horizontal equity, that all patients potentially accessing care are equal, and should have equal treatment (Mooney and Jan, 1997). Few studies relate any aspect of referral or access to a measure of clinical need, patient/carer demand, or subsequent benefit from services. It may be that vertical equity is a more appropriate concept, that patients access care in unequal ways that are equitable because of their unequal needs.

Research into different patients’ access patterns also focuses attention on patient characteristics as a possible explanatory factor, rather than the potential impact of professional, service or organisational factors. Indeed, it could be said that the association between patient characteristics and access has been interpreted in some studies as causal, rather than an association. Ahmed et al. (2004) conclude from their review that future research should focus on determining the adequacy of provision of palliative care for those receiving inequitable care. A note of caution should be sounded, as the assumption of inequitable care may be incorrect, and the provision of care has not been shown to be inadequate.

Much of the research reviewed employs quantitative methods, with a preponderance of retrospective analyses of routinely available data and survey approaches. Whilst there is no question that many of these are appropriate and rigorously conducted studies, the impact of such choices is that areas to study are essentially pre-determined. It is noted in section 2.3.5 that these choices appear to
restrict the issues examined regarding what facilitates or acts as a barrier to professionals’ referral practices. A research approach which facilitates the discovery of unanticipated influences, and allows an in-depth understanding of what affects referrals may therefore be appropriate when studying this area further.

Patients’ and carers’ views are also notably absent from much of the research reviewed, although this is a field which appears to be rapidly expanding. It appears that patients also note professional barriers to referrals, and that their own views on care can affect referral practices. It may be appropriate therefore for any study investigating influences on referral practices to incorporate the views of patients or carers.

The focus of the research reviewed is primarily referrals to specialist palliative care services. There are few studies which either assess referrals to more general services, or investigate the potential dynamic between specialist and general care which may affect patient access. Again, this is an area which warrants further investigation.

In conclusion, most studies reviewed use quantitative methods to investigate whether or when patients are referred to or access (specialist) palliative care services, not the processes preceding referral. There is a sound understanding of what is happening, but not of how or why. There are also poor descriptions in many studies of the context of care and hence decision making practices. There is an emerging literature exploring professional and patient related barriers to referral. This indicates that professional knowledge about services and the attitudes of patients and professionals towards services may have an impact on referral practices. However, there is an absence of published research investigating in detail the reasons given, and factors influencing a professionals’ decision to refer a patient to particular palliative care services, provided by generalists and specialists. It is this omission that this study sought to address.
Chapter three

Research methods – choice of method
3.1 Introduction

This chapter presents the research questions, aims, and objectives of the research, and debates the research methods which could be appropriate to answer these. The research method chosen is then discussed in more detail. The working methods of the study are presented in chapter 4.

3.2 Research aims and objectives

The literature review in chapter 2 presents a comprehensive overview of research in the field of access to community palliative care services. Whilst this demonstrates referral patterns that may be sub-optimal to achieve equitable, appropriate and timely referrals, there is less understanding of why these patterns of referral and access occur. Factors which facilitate or block referrals from health care professionals may be important to understanding why referrals are made, but this research is limited in its scope. There is also little understanding of the role those providing general palliative care play, both in receiving referrals and providing care, and in making referrals to others.

This research sought to address this deficit by describing the reasons given for, and influences on health care professionals’ referral practices within community general and specialist palliative care services.

The aim, research questions and objectives of the research are stated below.

**Aim**

To describe the reasons given for and influences on the referral decisions made by healthcare professionals providing community general and specialist palliative care services.

This aim led to the formulation of two ‘how’ and ‘why’ questions to facilitate the description of these reasons and influences and to state an interest in the local context of such decision making. Four research objectives are also broadly stated. These objectives were developed to guide how and from whom data could be
collected, and are deliberately broad to facilitate discovery of unknown factors which could affect referrals. They were developed to reflect issues identified as important or absent in the literature review and discussed in section 2.4: the context of care; the unknown personal and professional influences on referral; and the potential influence of patients on referral. The policy context of any study into referral practices is also acknowledged as a potential influence.

**Research questions**

How are referral decisions made by healthcare professionals providing general and specialist community palliative care services within defined localities?

Why do those providing general and specialist community palliative care services within defined localities make the referral decisions they do?

**Objectives**

a. To describe and map the local structures and processes of community general and specialist palliative care services within the context of their localities.

b. To investigate public and published factors which could influence referrals made by providers of community general and specialist palliative care services within defined localities.

c. To investigate individual and personal factors which could influence referrals made by providers of community general and specialist palliative care services within defined localities.

d. To investigate whether the referrals made by community general and specialist palliative care services met the expectations of patients within the defined locality, and how patients influenced referral processes.
3.3 Study design

3.3.1 Choosing an appropriate design

Having defined the research aim, questions and objectives, the next step was to select an appropriate research design. This choice is key to ensuring that research questions are addressed in a way which has value and is congruent with the overall topic, questions, and purpose of the research.

Five dimensions can be considered when choosing an appropriate research design: control over independent variable; degree of structure; type of group comparisons; number of data collection points and occurrence of independent and dependent variables (Polit and Hungler, 1999). Table 3.1 summarises the advantages and disadvantages of the design choices which could be made to address the research questions posed in this study.

Table 3.1 Advantages and disadvantages of different research designs to answer the research questions posed in this study
After Polit and Hungler (1999) p.161

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Design</th>
<th>Advantages of design for this community palliative care study</th>
<th>Disadvantages of design for this community palliative care study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control over independent variable</td>
<td>Experimental</td>
<td>Able to compare outcomes of different palliative care services and interventions.</td>
<td>No appropriate independent variable to manipulate. No utility in understanding structures and processes of care. Not exploring new intervention, so no identification of control and experimental groups. Suitable only to answer a different question.</td>
</tr>
<tr>
<td>Quasi experimental</td>
<td></td>
<td>Overcomes difficulty of control group identification.</td>
<td>Difficult to identify appropriate independent variable.</td>
</tr>
<tr>
<td>Non experimental</td>
<td></td>
<td>Utility in exploring and understanding under-researched topic. Able to explore structure and process.</td>
<td>Cannot determine cause and effect.</td>
</tr>
<tr>
<td>Dimension</td>
<td>Design</td>
<td>Advantages of design for this community palliative care study</td>
<td>Disadvantages of design for this community palliative care study</td>
</tr>
<tr>
<td>-----------</td>
<td>--------</td>
<td>-------------------------------------------------------------</td>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>Degree of structure</td>
<td>Structured</td>
<td>Structure helps control the volume of data collected. Prior knowledge and theory can be used to guide specification of design.</td>
<td>Unable to respond to discoveries/issues during the collection of data.</td>
</tr>
<tr>
<td></td>
<td>Flexible</td>
<td>Able to respond to discoveries/issues during the collection of data.</td>
<td>Need to keep close focus on research question to prevent collection of inappropriate data.</td>
</tr>
<tr>
<td>Type of group comparison</td>
<td>Between-subjects</td>
<td>Able to investigate different groups of professionals and patients in receipt of different community palliative care services.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Within subjects</td>
<td>Able to investigate same patients receiving different community palliative care services. Need to look at same professionals/services providing care to different patients.</td>
<td></td>
</tr>
<tr>
<td>Number of data collection points</td>
<td>Cross-sectional</td>
<td>Captures processes at a moment in time i.e. snapshot of different patients at different stages in illness. Practical and economic.</td>
<td>May be alternative explanations for time sequencing not captured by cross sectional design.</td>
</tr>
<tr>
<td></td>
<td>Longitudinal</td>
<td>Time dimension may be important: how processes of care change time; temporal sequence of referral/assessment/intervention events.</td>
<td>Time consuming. Potential problems with attrition of research participants, particularly patients in the palliative phase of illness.</td>
</tr>
<tr>
<td>Occurrence of independent and dependent variables</td>
<td>Retrospective</td>
<td>Able to incorporate temporal dimension. Analysis of antecedents may determine how community palliative care services have been derived and responded to different policies etc.</td>
<td>No dependent variable – not exploring causation/outcome.</td>
</tr>
<tr>
<td></td>
<td>Prospective</td>
<td>Able to incorporate temporal dimension. Able to explore changes in structure and process of community palliative care services over time.</td>
<td>No independent variable. No indication of speed of change of structures and processes, so likely to take too long for current timescale.</td>
</tr>
</tbody>
</table>
Assessing the relative merits of each approach allows conclusions to be drawn about which design features are congruent with the research topic:

- **Control over independent variable.** A non-experimental approach has utility in understanding under-researched topics, and exploring structure and process where no independent variable has been identified.

- **Degree of structure.** Some structure is necessary to control the potential volume of data. A degree of flexibility is needed to respond to discoveries and issues.

- **Type of group comparisons.** Both between subjects and within subjects comparisons are required to look both at how professionals/services provide community palliative care and referrals to different patients, and how different professionals respond to the care and referral needs of the same patient.

- **Number of data collection points.** A cross-sectional approach captures the structure and processes of community palliative care services at a moment in time. However, some longitudinal element is required to locate the temporal sequence of the referral, assessment and intervention process.

- **Occurrence of independent and dependent variables.** A temporal element is important to examine the sequence of the referral processes. The presence of multiple influencing variables militates against identification of dependent or independent variables.

A non-experimental approach appeared most appropriate. However, there are numerous non-experimental approaches. Each of these approaches offered a means of exploring an element of the way community palliative care services operate (Creswell, 1998). For example, an ethnographic approach may be useful in exploring the meanings and experiences of particular palliative care ‘cultures’, a grounded theory approach would facilitate explaining the stages and phases that characterise the palliative care journey, or a survey approach could collect information on community palliative care services from those who refer to them.

One approach that meets the criteria above and has utility in addressing the complexity of the question, placed in its real life context is case study. Yin (2003a) identifies the case study as the most appropriate research strategy when ‘a how or
why question is being asked about a contemporary set of events over which the investigator has little or no control'. This mirrors the issues in this research where a how or why question is asked about a contemporary issue (referral within community palliative care) within a real life setting (the context of the provision of community palliative care services). Its utility to address these research questions is therefore explored in more detail. As previously highlighted, some of this section draws from work previously published (Walshe et al., 2004).

3.3.2 Case study strategies and the research questions

3.3.2.1 Defining case study

Case study research strategies are difficult to characterise because many of their features are found in other research methods and designs. Case studies, for example, often use multiple methods such as interviews or observation, which can be found in approaches which are not case studies. Thus case study can mean different things in different research traditions (Sandelowski, 1996; Cunningham, 1997; Appleton, 2002). Case studies can use either or both qualitative and quantitative methods, can be prospective or retrospective, can have an inductive or deductive approach to theory, can focus on one case or many, can describe, explain or evaluate. Consequently it is unsurprising that there is ambiguity in understanding what case study is (Gilgun, 1994; Appleton, 2002). It is important to appreciate that case study is an approach or strategy, not a methodology. Case study strategies allow different data collection methods to be used, as long as they are appropriate to the research questions posed.

Case studies do have defining features, which differentiate them from other strategies. A clear definition of case study, and one which is found most frequently in case studies in palliative care is that of Yin (2003a):

‘A case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident’. (Yin, 2003a p.13)
In contrast, Stake (1995), another key author, describes case study strategies more loosely – focusing instead on defining the case:

‘a specific, a complex, functioning thing … with each case being an integrated system with a boundary and working parts’. (Stake 1995 p2)

Whilst he draws attention to similar rationales for choosing case study (a contemporary issue, in real-life settings, with no researcher control, using multiple sources of evidence) he places much less emphasis on the methods chosen to study the case, and there is no insistence on the use of theoretical propositions or the development of theory.

The competing definitions underline a philosophical difference in approach to case study as a research strategy. Whilst case study is most often placed within a qualitative paradigm (Keen and Packwood, 1995; Mariano, 2001), many of its proponents, especially Yin (2003a), would identify an approach to case study design more closely aligned to research using a quantitative or positivist approach (Appleton, 2002; Lloyd-Jones, 2003). However, whilst there are differences in philosophical underpinnings and data collection approaches, there are core elements implicit in every case study approach: the case (or bounded system), multiple sources of information, and the context of the case (Creswell, 1998; Stake, 2000; Verschuren, 2003; Yin, 2003b).

### 3.3.2.2 The appropriateness of a case study strategy

Palliative care is complex, patient focused, context dependent and multi-professional (Clark and Seymour, 1999). These characteristics mirror the advantages of a case study strategy: its breadth, its collaborative approach, its recognition of complex contexts, the use of multiple research methods, a realistic focus on process and outcome, and its flexible yet rigorous approach (Robson, 2002). Case study strategy may be appropriate in palliative care research when complex situations need to be addressed, when context is central to the study, when multiple perspectives need to be recognised, when the design needs to be flexible, when the research needs to be congruent with clinical practice, when there is no strong theory to which to appeal, and when other methodologies could
be difficult to conduct. These issues are now briefly addressed to consider whether a case study strategy is appropriate for this research.

**When complex situations need to be addressed**

An early assessment of palliative care research concluded that the dynamic and complex nature of dying requires robust methods which can examine and expose that complexity (Twycross and Dunn, 1994). There seems to be a direct resonance between this need to deal with complexity, and Yin’s (2003b) assertion that case study strategies are appropriate to study complex multivariate conditions and not just isolated variables. Complex fields in health, social work and education recognise the potential of case study (Hammersley, 1985; Anleu, 1992; Shortell, 1999).

In this study, the situation to be investigated appears complex, with community general and specialist palliative care services investigated likely to comprise provision from NHS, voluntary and local authority providers, each with a range of different professionals contributing to care. In addition, the literature review in chapter 2 reveals multiple potential influences on referral practices indicating that the influences are likely to be complex.

**When context is central to the study**

Researchers choosing a case study strategy believe that situational factors have a direct effect on the phenomenon under study (Woods, 1997; Anderson et al., 2005). Case studies are apt when the question posed requires an investigation of a real life intervention in detail, where the event may be ill-defined or not discrete, where the focus is on how and why the intervention succeeds or fails, where the general context will influence the outcome, and where researchers asking the questions will have no control over events. Palliative care studies using a case study approach have seized on the importance of context to justify their choice of method (Bergen, 1992; Cowley et al., 2001; Skilbeck et al., 2002; Lee, 2002).

In this study, palliative care provision is likely to differ between different localities, and it is possible that different contexts and different ways of providing services
may have significant impacts on the way referrals are made. A research approach which takes account of context therefore appears vital.

**When multiple perspectives need to be recognised**

There appear to be two main threads to the recognition of multiple perspectives: collaborating with stakeholders and using a diversity of methods and sources (Ingleton *et al.*, 1997). Most case study literature particularly emphasises the strength of using different sources of evidence to investigate a phenomenon (Yin, 2003a).

Much of the current work presented in chapter 2 focuses on the provision of access to specialist palliative care services, rarely recognising the impact of other services on care and access to care. This research aims to address this deficit by examining the impact on access to services of all services providing community palliative care in an area, and therefore the perspectives of many need to be recognised.

**When the study design needs to be flexible**

Case studies can be used for many purposes – exploring (new areas), describing (complex events or interventions), and explaining (complex phenomena) (Kohn, 1997). Within these purposes it is possible to adapt the design of the case study to meet different practical, ethical and theoretical considerations. This adaptability is a methodological strength (McDonnell *et al.*, 2000).

This flexibility of design was important in this research because there is little evidence in the field, with previous studies often reliant on survey or retrospective routinely collected data which may not explore all relevant issues. A flexible approach to study design facilitated the pursuit of unexpected avenues of inquiry in a rigorous way.
When you want the research to be directly congruent with a clinical practice approach

Case study can be a realistic study of practice, and thus has a strong and obvious relationship with practice. It has been used extensively in practice oriented disciplines as a way of addressing the holistic nature of care and treatment (Gray, 1998). Findings address both practice issues, and the environments within which practice is embedded. Many of the everyday decisions health care professionals make are intuitive, tentative and variable, and case studies are argued to be sufficiently flexible to respond to these issues (Keen and Packwood, 1995; Jensen and Rodgers, 2001).

It could be argued that research into referral practices which appear to promote inequities should have the ultimate aim of facilitating changes in referrals, and therefore to be a direct influence on practice.

When there is no strong theory to which to appeal

Case study researchers argue that the strategy is useful in situations where there is no strong theory on which to base a study (Bozeman and Klein, 1999). Whilst there has been robust debate about the role of case studies in producing valid theories (see for example, Dyer and Wilkins (1991) and Eisenhardt (1989)), the object of many case studies is to generate and test theory (Hammersley, 1985). Theory can be defined in broad terms as an explanation of situations or phenomena, ranging from formal academic theories to speculations made by research participants (Robson, 2002). Of the two key writers on case study strategies (Yin and Stake), Yin (2003a) particularly emphasizes the importance of theoretical propositions. He argues that the role of theory development, prior to data collection, is a key difference between case studies and other related methods such as ethnography. He suggests that the development of theoretical propositions from the research questions, literature, and exploratory work is often key to the case study, guiding both data collection and its analysis.

As it has been argued that palliative care itself has no clear theory, no clear agreed meaning, and no criteria for success or outcome indicators, then a strategy
which can both take account of that, and potentially generate theory may be appropriate (Abma, 2001). The literature reviewed in chapter 2 is also not overtly theoretical, although concepts of equity could be argued to underpin many studies. Certainly there appears to be no strong theory regarding the influences on palliative care professionals’ referral behaviour upon which to base the study, further supporting the choice of a case study strategy.

**When other research methodologies could be difficult to conduct**

Whilst the arguments for the use of case study in this study could not and should not be based wholly on the deficiencies of other research methodologies, as suggested earlier, there is a growing literature in palliative care pointing to the difficulties of operationalising some techniques in this field.

Difficulties in study recruitment, attrition, randomization, timing and ethics have been particularly reported in experimental work in palliative care (Jordhøy et al., 1999; Grande and Todd, 2000; Ewing et al., 2004). Whilst case study research strategies rarely have to deal with randomization, issues of recruitment, attrition, timing and ethics can still be problematic. However, unlike experimental studies which rely on specified levels of recruitment to achieve power calculations, case study researchers often have the flexibility within a rigorous approach to work effectively within these constraints and still produce high quality, relevant work.

Experimental approaches were rejected for use in this study as inappropriate to answer the questions posed, and so some of these issues are not wholly relevant. However, recruitment issues may be an issue, and a case study strategy is one approach which would allow completion of a rigorous study in these circumstances.

**The limitations of case study approaches**

Case study research, like all research approaches, is not without its difficulties and limitations. Indeed, case study strategies have been highly criticised by some commentators on a number of issues, principally that they produce poor quality results, that the strategy is methodologically ambiguous, and that the results are
not generalisable (Jensen and Rodgers, 2001; Verschuren, 2003; Flyvbjerg, 2004). The difficulties in defining exactly what case study strategies are have probably contributed to such criticisms. Understanding case study strategies often hinges on definitions which focus on the case(s) under study rather than a way of doing the research (Verschuren, 2003). Because the methods to be followed are rarely specified by case study authors (e.g. Yin 2003a, Stake 1995), and can be drawn from different research traditions, with different philosophical underpinnings, then confusion arises regarding how to interpret the quality of the research and its results, and whether and how the results may be generalisable (Gomm et al., 2000; Verschuren, 2003).

Proponents of case study research strategies acknowledge its limitations. Empirical generalisation may not be possible, control of behavioural events does not happen, and causality cannot always be determined (Yin 2003a). In addition, case study research is acknowledged to be time consuming and complex (Yin, 1981; Lloyd-Jones, 2003). However, authors also argue cogently that some of the above criticisms of case study are not warranted, and that case study is a necessary and sufficient method when used to study appropriate questions (Flyvbjerg 2004). Indeed, the very ambiguity criticised by some authors is seen as a strength by others who applaud its broad application, and epistemological, ontological and methodological flexibility (Luck et al., 2006).

The difficulties of case study research alluded to above are taken account of in this study, and discussed where necessary in describing the conduct of the study and its strengths and limitations.

3.4 Summary

The basic concern should always be that the approach chosen is appropriate to answer the research question posed, and researchers must scrupulously consider all methodological options for each new piece of research (Jowett, 1997). Whilst a case study design is not the only research strategy which could be appropriate, it appears the most appropriate design to answer the questions posed.
A descriptive case study strategy was therefore employed within this study. It is not possible in this section to discuss a ‘case study approach’ to data collection or analysis, as such issues are dependent on the choice of methods. These issues are therefore discussed in the next chapter when the way that a case study was used in this study of referrals within community palliative care services is discussed.
Chapter four

Research methods – working methods
4.1 Introduction

Chapter 3 set out the congruence between the research topic and the selection of a case study strategy. This chapter sets out the conduct and methods of the study, presenting the approach to case study adopted. The rationale for the choice of particular data collection methods is given, information about data actually collected, and any issues arising from data collection presented. Details of the analytical procedures are also given. This integration of method, data collection and analysis reflects the iterative nature of the study, where the initial analysis of data influenced the data then collected.

Having selected a descriptive case study strategy to study what influences referrals within community general and specialist palliative care services, choices were then made regarding other elements of the research design: the study propositions; units of analysis; number of cases to be studied; and data collection methods. These are now examined in turn.

4.2 Study propositions

A theoretical framework or set of theoretical propositions does not necessarily mean causal theories in this situation, rather it means the design of research steps according to some relationship to the literature, policy issues or other sources (Yin, 2003b). Propositions focus attention on what should be explored in the study and can also reflect researcher’s intuitions (Mariano, 2001). Yin (2003a) explains that the aim is not grand theory, but to have a sufficient theoretical blueprint for the study to guide the research design, data collection and data analysis. Theoretical propositions can be a hypothetical story about why acts, events, structure and thoughts may occur (Yin 2003a). Theoretical propositions are constantly re-visited during the study, examined in the light of new data, and amended as necessary, in a way which has been compared to the constant comparison used in grounded theory (Eisenhardt, 1989; Cowley et al., 2000; Cowley et al., 2001). The iterative refinements and amendments to the propositions can then become the main vehicle for generalising the results of the case study (Yin 2003a).
Merriam (1998) suggests that studies are partly theoretically framed by the way the aims, research questions and objectives of the study are set out and as discussed in section 3.2 these are explicitly drawn from the findings of, and gaps identified in, the literature review. However, theoretical propositions also suggest an initial ‘story’ about why acts occur. Four theoretical propositions were therefore also developed, in addition to the research questions and objectives, as an initial focus for data collection. These propositions were developed from two sources. First, they emerged from the literature reviewed in section 2.3.5 which identifies the current knowledge about what factors act as barriers to or facilitate referrals from professionals to community palliative care services. Second, they reflect my personal experiences working in community palliative care settings. The use of researcher intuition in theoretical propositions is acknowledged by others, and also makes explicit any assumptions and biases of the researcher (Mariano, 2001).

From these elements, four initial theoretical propositions were developed. These formed a focus for data collection, and were constantly revisited and revised during the collection and analysis phases of the study.

1. Professional roles and responsibilities are constantly re-negotiated around the care needs of individual patients.
2. Caring for palliative care patients is ‘special’ and the status this confers on professionals affects the referral choices they make.
3. Professionals have a sense of ownership and responsibility towards palliative care patients, and this affects their gate keeping role in referral to and work with other professionals.
4. The culture and context of individuals, teams, and organisations providing palliative care will affect referral patterns.

These propositions are re-presented in chapter 9 as the final iteration developed from continual revisions during data collection and analysis.

4.3 Defining the case

Yin (2003a) describes the case as a contemporary single unit or phenomena of study examined in context, where the boundaries between phenomena and
context are not clearly evident. He makes it clear that the definition of the unit of analysis (and therefore of the case) is related to the definition of the research questions.

The objectives of this study help to specify the boundaries of the case by stating an interest in community general and specialist palliative care services provided within a defined locality. The principal organisational structure in English primary health care at the time of this study was the Primary Care Trust. Primary Care Trusts were responsible for the commissioning or the provision of most community health care services (Department of Health, 2002) including palliative care for a defined area. This area was defined with reference to both geography, and the patients registered to the General Practitioners (GPs) within that area.

The case was therefore defined as ‘those services providing community general and specialist palliative care to patients registered or residing within a specified Primary Care Trust’.

For this study ‘community care’ means care delivered within the patient’s home setting, or care delivered in a non-hospital setting whilst the patient remains living at home. ‘General palliative care’ refers to care provided by those who do not specialise in palliative care provision, and who take a palliative care approach. ‘Specialist palliative care’ refers to care provided by those who specialise in palliative care provision. (After Tebbitt, 1999). This definition of the case focuses attention on referrals made within the community setting, and excludes those made from outside the case (for example hospital services).

Yin (2003a) also identifies that a case study may involve more than one unit of analysis, when attention is given within the case to subunits. He refers to this as an embedded case study design. For this research, a rational sub-unit for analysis would be the individual services that provide community general or specialist palliative care as each service may operate under distinctive operational policies and procedures, and with different influences on referral.

A unit of analysis smaller than the case was therefore defined as ‘Each distinct provider of general or specialist palliative care services to patients registered or residing within a specified Primary Care Trust.’
Once the case had been identified the design of the study was chosen. There are two basic designs used in case study research; single case design and multiple-case design. A single case design is used when the case represents a typical case, a critical case, an extreme or unique case or a revelatory case, or when the same case is studied at more than one point in time (Yin, 2003a). A multiple case design is used in establishing whether a proposed explanation is confirmed across a number of cases, and in exploring the same phenomenon in a diversity of situations (Mariano, 2001). Each case should be selected so that it predicts similar results (literal replication) or contrasting results but for predictable reasons (theoretical replication) (Yin, 2003a). Stake (1995) sounds a pragmatic note, cautioning that only a few combinations of theoretical propositions or variables will usually be possible.

For this research, a multiple case study approach was conducted. This was felt appropriate when typical, critical or unique cases were not known. Studying multiple cases would also allow assessment of similarities and variability in referral practice across Primary Care Trusts with different characteristics and serving different populations. The overall design of a multiple case study which this study followed is depicted in figure 4.1.

It can be seen from this that the next stages of the study were to select the cases and design the data collection protocol. Both of these activities require sampling decisions, and these are considered next.

4.4 Sample

In a case study there are two dimensions of sampling to be considered: the choice of case(s), and the choice of data sources within the case.

4.4.1 Choice of cases

The choice of case is not random. Kohn (1997) emphasises that cases are not selected to statistically represent some population. The decision in a multiple case study design about how many cases to study is one based on knowledge of appropriate theoretical propositions, together with an appreciation of the resources and time constraints of the study.
Figure 4.1 Diagram depicting the case study design and method (after Yin 2003a p.50)
For this study, cases were primarily selected according to the way their specialist palliative care services were configured. Attention was also paid to the demography of the area they served. Selection therefore took some account of the culture and context of individuals, teams and organisations suggested by the fourth theoretical proposition.

Primary Care Trusts’ palliative care service configurations were identified on the basis of public data available from Hospice Information (2002) and the Palliative Care Survey (The National Council for Hospice and Specialist Palliative Care Services, 2000). In addition, demographic information was accessed from the national statistics website (www.statistics.gov.uk), and information about some of the characteristics of general providers accessed from the national database of primary care groups and trusts (www.primary-care-db.org.uk).

Using this information three Primary Care Trusts in the North West of England were selected that appeared to differ in the way their specialist palliative care was organised, but which had some similarities in the social mix of patients potentially using the services. Trusts were approached that respectively had a large multi-professional palliative care team based around a large well established hospice, or an emergent multi-professional team based around a much smaller hospice, or only had access to a nurse-led team within the Primary Care Trust borders. Such differences may affect referral practices, anticipating theoretical replication – different results for predictable reasons.

Each of the three initial Primary Care Trusts selected from this process agreed to take part. The Primary Care Trusts are described further in chapter 5.

4.4.2 Choice of data sources

Both Stake (1995) and Yin (2003a) emphasise the importance of creating a structure for data collection within a case study. All data gathered should be deeply rooted in the questions, and each question or objective should have sources of data attributed directly to it. This structure was followed within this study, with data sources chosen because they were likely to provide information pertinent to the objectives of the study.
This information is presented in tabular form (Table 4.1), with the objectives of the research related to data collection sources and methods of collecting data from this source.

4.5 Identifying data sources within the cases

Following decisions about the likely sources of data and data collection methods to address the objectives of the research, issues of sampling and recruitment were addressed.

4.5.1 Sampling and recruitment of professional participants

Professionals were invited to participate in the research either because they were perceived as ‘key informants’ who could provide information about general or specialist palliative care services and their contexts within the Primary Care Trusts (patient interface, management, commissioning), or else they were professionals who made or received referrals for patients in the palliative phase of their illness. It was anticipated that they had the knowledge and experience to inform the research question, the ability to reflect, and be willing to participate (Morse, 1994).

Health care professionals and key informants were eligible for inclusion if they were:
- Working with patients within the Primary Care Trust geographical boundaries
- Either working with patients to provide community palliative care and/or able to comment on the provision of community palliative care services within the Primary Care Trust.

Key informants and some health care professionals (principally the specialist palliative care staff) were selected purposively. Initial meetings with staff within the Primary Care Trusts to introduce the research usually highlighted potential informants who might be able to provide rich data, usually because of their role within the Primary Care Trust – as a commissioner or manager of palliative care services, or a provider of specialist palliative care.
Table 4.1  Proposed methods of data collection

<table>
<thead>
<tr>
<th>Research objective</th>
<th>Sources of data</th>
<th>Data collection method</th>
<th>Justification of method</th>
<th>Sampling issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>To describe and map the local structures and processes of community general and specialist palliative care services within the context of their localities</td>
<td>National and local directories of services</td>
<td>Document analysis</td>
<td>Pre-existing record which should be relevant</td>
<td>Identification and retrieval of documents</td>
</tr>
<tr>
<td></td>
<td>Local palliative care policies and strategies</td>
<td>Document analysis</td>
<td>Pre-existing record which should be relevant</td>
<td>Identification and retrieval of documents</td>
</tr>
<tr>
<td></td>
<td>Key informants within the Primary Care Trust</td>
<td>Semi-structured interview</td>
<td>Focuses directly on case study topic, with potential for unanticipated data to emerge</td>
<td>Purposeful sample of informants – snowball technique to be used, until no new themes emerge</td>
</tr>
<tr>
<td></td>
<td>Epidemiological data on palliative care needs in the locality</td>
<td>Data collected to complete needs assessment (Tebbit, 2004)</td>
<td>Method of assessing need and understanding provision/context promulgated by Department of Health/local cancer networks</td>
<td>Availability of data/access granted</td>
</tr>
<tr>
<td>To investigate public and published factors which could influence referrals made by providers of community general and specialist palliative care services within defined localities</td>
<td>Primary Care Trust and/or individual service referral and assessment protocols</td>
<td>Document analysis</td>
<td>Pre-existing record which should be relevant</td>
<td>Identification and retrieval of appropriate documents</td>
</tr>
<tr>
<td></td>
<td>Documentation of referral in referral forms and case notes</td>
<td>Document analysis</td>
<td>Pre-existing record that should contain relevant data</td>
<td>Case notes studied for patients who have consented to participate in the study</td>
</tr>
<tr>
<td></td>
<td>Routine referral information collected for minimum data set requirements</td>
<td>Aggregation of routinely collected data, where available</td>
<td>Pre-existing record that should contain relevant data</td>
<td>Identification and retrieval of appropriate data</td>
</tr>
<tr>
<td>Research objective</td>
<td>Sources of data</td>
<td>Data collection method</td>
<td>Justification of method</td>
<td>Sampling issues</td>
</tr>
<tr>
<td>--------------------</td>
<td>----------------</td>
<td>------------------------</td>
<td>-------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>To investigate individual and personal factors which could influence referrals made by providers of community general and specialist palliative care services within defined localities</td>
<td>Interviews with professionals making and receiving referrals within the Primary Care Trust</td>
<td>Semi-structured interviews</td>
<td>Focuses directly on case study topic, with potential for unanticipated data to emerge</td>
<td>Sample likely to include all available specialist palliative care workers and a sample of general workers (GP/DN/others identified in mapping). A mixture of random sampling (to select generalists) and purposive sampling (to select specialists and those likely to be useful informants)</td>
</tr>
<tr>
<td></td>
<td>Observation of referral team meetings</td>
<td>Non-participant observation of scheduled team meetings to discuss referral</td>
<td>Focuses directly on case study topic, with potential for unanticipated data to emerge</td>
<td>Presence of referral meetings. One meeting of each type to be observed for each professional observed/interviewed</td>
</tr>
<tr>
<td>To investigate whether the referrals made by community general and specialist palliative care services met the expectations of patients within the defined locality, and how patients influenced referral processes</td>
<td>Interviews with patients who have been referred to one or more palliative care professionals/services</td>
<td>Semi-structured interviews</td>
<td>Focuses directly on case study topic, with potential for unanticipated data to emerge. Allows comparison of professional's interpretation of referral with the patients</td>
<td>Each professional interviewed will be asked to nominate a patient</td>
</tr>
</tbody>
</table>
Occasionally generalists such as district nurses, general practitioners or allied health professionals with a special interest in palliative care were identified during this process. Initial interviews within the case study site were also used to generate information about key people to interview. This is essentially ‘selective’ or ‘purposeful’ sampling of those likely to have pertinent information (Coyne, 1997), using a ‘snowball’ technique because there was no sampling frame of those with palliative care interests within the cases (Heckathorn, 1997; Faugier and Sargeant, 1997). This bias such techniques can introduce because they rely on personal interrelationships is acknowledged.

Other informants, generally district nurses and general practitioners, were selected from listings of professionals provided by the Primary Care Trust. Whilst professionals were selected from these lists arbitrarily, once one professional had been selected, efforts were made to recruit ‘pairs’ of district nurses and general practitioners who worked together. The intention was to facilitate gathering data which reflected how those who may provide care for the same patients (i.e. district nurse, general practitioner, and specialist palliative care staff) viewed referral. In site ‘C’ lists of community staff nurses were also made available.

Letters of invitation, a response sheet, information sheet and stamped addressed envelope were sent to each individual identified as part of this process. The letters to non-health care professional key informants differed slightly, to take account of the different content of these interviews, and the non-patient contact nature of their posts. These are found in appendices 4, 5, 6, 7 and 8. Individuals from different professional groups were all invited to participate at the same time, so that data collection (and hence analysis) was constantly informed by the views of those from different backgrounds.

Those responding positively were contacted as soon as possible to discuss the study further and to arrange a mutually convenient time for interview. At least 24 hours elapsed between invitation and contact because the positive responses were received by post. Those responding negatively were eliminated from the study. Non-responders were followed up with a telephone call (as specified in the invitation letter), or a further letter of invitation if telephone contact could not be made. Recruitment of participants (health care professionals and key informants)
ceased either when new themes emerged from data analysis within that case, or all relevant informants within the case were recruited (Morse 1994).

Interviews were conducted face to face in a place of the participants choosing, generally health care premises such as a health centre or surgery. An opportunity was given to discuss the study further, and written consent obtained for the interview and for it to be recorded (appendix 9).

### 4.5.2 Sampling and recruitment of patient participants

Each health care professional who agreed to participate in the study was asked to recruit a patient in the palliative phase of any illness. This was discussed further with the health care professional at the time of their interview, the patient recruitment information given to them and the opportunity to discuss this offered. The letter of information to the health care professional about recruitment, the patient letter, response sheet and patient information sheet are found in appendices 10, 11, 12 and 13. These do not mention palliative care – rather patients are invited to participate in a study of referral in community health care services. This was requested by the research ethics committees for three reasons: first, the term ‘palliative’ could be one which patients might not understand; second, patients may not be as cognisant of their diagnosis and prognosis as the professional believed; third, patients may not wish such information to be available to others to read within their homes.

Health care professionals were asked to recruit a patient they were currently caring for who had recent experience of referral to a service – either because they were recently referred to their own service, or had been referred to a different service. This method of recruitment maximised opportunities to interview those with relevant experiences, but risked recruiting those patients that professionals thought may reflect well on their own services. Discussing a range of services with a range of patients may ameliorate this bias. Inclusion criteria were developed, and discussed with the recruiting health care professional.
Inclusion criteria:

Patients were eligible for inclusion if they were:

- Adults (age 18+, no upper age limit).
- Assessed by their health care professional as being in the palliative phase of their illness.
- Assessed by their health care professional as being able to understand and consent to participation in the research.
- Aware of their diagnosis and prognosis.
- Referred to a service providing general or specialist community palliative care.

It was emphasised to the health care professional that there should be an equal opportunity to participate in the research regardless of gender, disability, ethnicity or language spoken. Information from key informants, health care professionals and patient participants was sought about any particular additional resources they may need to participate or to recruit particular individuals i.e. native language speakers, translations of information sheets, escorts etc.

The patient invitation letter was handed or posted to potential patient participants by their health care professional. The letter advised that patients could speak with any of their usual health care providers before deciding to participate, if they so wished. Patients were further advised of an independent contact person from the study advisory group, whom they could contact if they wished to ask questions about the study. Patients were asked to return a reply slip, with contact details, to the researcher – thus ensuring that more than twenty-four hours elapsed prior to the individual being recruited into the study (as requested by the ethics committees). If more than 48 hours had elapsed between posting this acceptance (from the postmark) and its receipt by the researcher, then the health care professional was contacted to ensure that there had been no change in the patient’s circumstances in the intervening period. The patient was then contacted to arrange a mutually convenient time to meet. Before interview an opportunity was given to discuss the study, answer any remaining queries, ensure the individual fully understood what was required of them and obtain written consent.
As suggested by the Primary Care Trust’s research governance protocols, the patient’s general practitioner was also informed of their participation in the study at this point, if the patient consented to this. Interviews were conducted face to face in the patient’s home, or other place of their choosing. Patients were given the opportunity to have another person present at the interview if they wished.

As part of the consent process, consent was also obtained to access the patient’s health care notes (appendix 14). Following the interview, letters (enclosing a copy of the patient consent form) were sent to the health care professionals identified by the patient as currently providing their care, requesting access to their notes. A data extraction form was used to record information from patient’s notes, and this is found in appendix 15.

4.5.3 Conduct of the interviews

Interviews are seen as one of the most important sources of case study information (Yin, 2003a). Yin (2003a) suggests that interviews should be like guided conversations, proceeding fluidly. The interviews in this study are what he calls ‘focused interviews’, where interviews are open-ended and assume a conversational manner, but where there are focused questions derived from the research questions, and from the data previously gathered. An initial topic guide was developed (appendix 16), and was amended in response to emerging lines of enquiry. There was no defined order to the questions asked or topics investigated, but respondents were encouraged to talk about their experiences through open ended questions and the ordering of further questions determined by their responses (Dearnley, 2005). Detailed field notes were also made during and immediately after the interviews to capture the context of the interview, non-verbal behaviour, and initial thoughts following the interview. With permission, all but one of the interviews were tape recorded. One participant declined to be recorded and extensive notes of the interview were made both during and after the interview. Interviews varied in length, most being around an hour. The shortest interview was 20 minutes, the longest 2 hours 10 minutes.

Attention was paid during the data collection and analysis phases of the study to the fact that interviews are socially constructed encounters. Interviewees were
likely to present subjective perspectives, shaped by personal contexts and the way they chose to present themselves and their views (Mischler, 1986; Kvale, 1996). People are known to have a tendency to present themselves in a socially acceptable way which affirms and maintains their self image (Sherman and Kim, 2005). These behaviours are acknowledged in this research, and the findings are presented as such – as personal representations of reality.

Interviews were transcribed verbatim, either by the researcher or by transcribers employed specifically for this purpose.

### 4.5.4 Collecting observational and documentary data

Non case-note documentary data was requested at the end of interviews with health care professionals and key informants. At the end of the interview participants were asked if they could provide or knew of any written information, minutes, policies, protocols, assessment proforma etc. which were pertinent to referral within community palliative care services or illuminated issues about the context of the case study. All such proffered documentary data were collected and analysed. In addition, documentary data were collected serendipitously for example in waiting areas, trust web-sites etc.

Health care professionals and key informants were also asked at the end of the interview if they were involved in any meetings either to discuss and/or refer palliative care patients, or meetings related to palliative care strategy/policy etc. Once any such opportunity had been identified, the participant was asked if they could request of the meeting attendees that I attend the meeting as a non-participant observer. Once the agreement of those attending the meeting had been obtained, then arrangements were made to attend and observe. The problems of observation are recognised, that observation of any social encounter or situation is likely to have an impact on the situation, and that data collected in such situations is a personal interpretation (Nandhakumar and Jones, 1997). At such formal observation opportunities detailed field notes were made during and after the period of observation.
Casual observation is also possible during a case study. It is suggested that observations may be made throughout a field visit, for example when interview evidence is collected, observing work spaces and the layout of the building may indicate something about the organisation and the position of the interviewee within it (Yin, 2003a). Such observations were made as interview field notes, or within the diary kept of the research progress.

4.5.5 Collecting contextual epidemiological data

Contextual epidemiological and health data were collected for each case study site to complete a palliative care health needs assessment (Tebbit, 2004). This information was collated from publicly available data (http://neighbourhoodstatistics.gov.uk) and from data provided by the relevant cancer network information teams and the Primary Care Trust information departments. More information about the sources of data is found in chapter 5.

4.5.6 Reflexivity

Reflexivity can be defined and approached in different ways (Cunliffe, 2003; Haggerty, 2003). It has been described as an insecurity regarding the basic assumptions, discourse and practices used in describing reality, and questions our relationship with the social world and the ways in which we account for our experience (Cunliffe, 2003). Cunliffe (2003) argues that it is necessary to go further than questioning the truth claims of others, to question how we as researchers and practitioners also make truth claims and construct meaning. Whilst reflexivity has been particularly associated with particular theoretical or methodological standpoints, it is also argued that it is impossible to be un-reflexive as it is an unavoidable feature of the way actions are performed, made sense of and incorporated into social settings (Lynch, 2000).

In this study, I felt it was important to make explicit my personal biography at the start of this research, and to acknowledge that my experience working in this field must inevitably have an impact on each element of the research process. The use of theoretical propositions allowed some of these potential impacts to be made
explicit, as they reflected intuitive thoughts about influences on referrals as much as the influences suggested by prior research and policy.

4.6 Ethical considerations

Most ethical concerns in research revolve around issues of harm, consent, deception, privacy and confidentiality (Punch, 1994).

4.6.1 Harm

Harm is particularly explored in palliative care research, with a focus on the vulnerabilities of palliative care patients, and the risks and benefits of palliative care research (Casarett and Karlawish, 2000; Jubb, 2002). Strategies to overcome vulnerabilities include assessing capacity, using a third party to approach patients, and emphasising voluntary participation. In this study a third person (the health care professional) was used to both assess capacity and initially approach patients. The voluntary nature of the participation was emphasised in the informed consent approach, and discussed with health care professionals at their interviews.

In this research the direct benefits of research to patient participants were intangible. In addition participating in research interviews is described as potentially exhausting and emotionally painful (Barnett, 2001). It is argued that patients perceive an altruistic benefit, participating to benefit others in the future (Rees, 2001). A suggestion has been made that interviews have the potential to be therapeutic if conducted by an experienced health care professional, willing to take time and discuss issues with patient respondents (Colbourne and Sque, 2004). An assessment of the potential risks and benefits to patients and professionals of this research was made explicit in both the application for study approval by research ethics committees, and in patient recruitment to the study.

The potential emotional distress of transcribing staff was also considered. The sensitive nature of the research was discussed with them in advance. Only one interview tape was initially released to them (with a health care professional), and
e-mail or telephone contact was made with them to ensure they were comfortable with the content matter before further transcription. They were forewarned of any tape (particularly tapes of patient interviews) likely to be emotionally difficult and opportunities to discuss any concerns about the tape or their response to it given (Gregory et al., 1997; MacLean et al., 2004).

4.6.2 Consent

Informed consent is central to the notion of ethical research, and was required from all participants. The challenges this posed were primarily administrative, not ethical. The concept of process consent was followed in this proposal, where consent was renegotiated at different stages of the interactions between the researcher and the participant (Beaver et al., 1999b). This took account of changes in physical or psychological state during the interview. Only one patient became visibly distressed during the interview, and they were given the opportunity to stop interviewing (which they declined), and to take time to compose themselves before continuing. Permission was sought to continue the interview, and other sources of help and information discussed.

4.6.3 Deception

No deception was intended with this research however, reference to the fact that this was research about palliative care was omitted from the documentation given to patients. Whilst patients should only have been recruited if health care professionals felt they knew their diagnosis and prognosis, this was a further safeguard against information going to patients who may not fully understand this. All patients interviewed openly discussed their diagnosis and prognosis, which may indicate that patients less likely to be open about such matters were less likely to be recruited. Other than this, the aims, objectives and processes of research were made transparent in the research documentation such as informed consent, letters requesting access, application(s) for ethical approval etc.
4.6.4 Privacy and confidentiality

These are considered together, as a major safeguard to privacy is the assurance of confidentiality (Punch, 1994). Privacy (or anonymity) can be an issue in case study research if the context reported allows identification of the case, and therefore of certain informants. Care has been taken to avoid sufficient detail being given to allow identification of the case, whilst preserving the description of the overall context of the case. All participants are referred to alphanumerically where the cases are referred to as case A, B or C, and participants by their background and by sequence in order of interview (GP = general practitioner, DN = district nurse, SN = specialist palliative care nurse, SD = specialist palliative medicine doctor, AH = allied health professional, KI = key informant, P = patient). Some subtle details about the case context (deemed not relevant to the findings of the study) have been altered to avoid case identification. Respondent characteristics (age, gender, qualifications etc.) are not given as the small number of respondents within each service (unit of analysis) would mean such characteristics may identify respondents if the case is identified.

Personal privacy during the research for patients was enhanced by conducting the research interviews in the patient’s own home. Whilst this may not facilitate privacy from carers (Beaver et al., 1999b), it ensured privacy from others, which may not be found in a public place. It was noted that the presence of carers affected the quantity and type of discussion about carers and their impact on referral.

The potential to discover inappropriate or sub-optimal care may affect confidentiality. In this situation I planned to advise the patient to contact their care provider (Casarett and Karlawish, 2000), and would not contact the provider without the patient’s permission unless the situation was judged urgent. Casarett and Karlawish (2000) believe that this position respects a patient’s right to preserve the confidentiality of information divulged, yet preserves an investigator’s obligation to subjects as patients. In the event, no care was discovered which warranted these actions being taken.

Stringent efforts were made to ensure that participants had not been involved in existing research prior to this study. However, this cannot always be known. This
issue was explored with the Primary Care Trusts when discussing their possible involvement with the study, and also with the individual health care professionals prior to inviting individual patients to participate. Because of the potentially vulnerable nature of palliative care patients, efforts were made not to interview patients who had previously been involved in research. This prior involvement, would not, however, interfere with their participation in this study if patients wished to participate.

The confidentiality of the tapes and transcript was also considered. Research material was stored in locked cabinets within a locked office. In addition, electronic information was password protected. All transcribers signed a confidentiality agreement prior to any tapes being dispatched.

4.6.5 Research governance and ethics approval

Approval to conduct the research was granted prior to the study commencing by the three local research ethics committees covering the Primary Care Trust case study sites. No particular ethical issues were raised by these committees except not using the word ‘palliative’ in patient documentation as previously noted. University of Manchester ethics committee approval was also sought and granted.

In addition, approval was also sought and granted from the research and development departments of the three Primary Care Trusts, following their research governance protocols. Three honorary contracts were granted and held within each Primary Care Trust. In addition, some of the staff participants in the study were employed by organisations other than the Primary Care Trusts. Permission was therefore sought and granted from three hospices, one local authority and one hospital trust to interview staff.

4.7 The data collected

Before consideration of data analysis techniques, it is pertinent to discuss the actual data collected in the study and address any issues arising from this data collection.
Data were collected from each case in a sequential, but overlapping way. This facilitated within case analysis before cross case analysis commenced. Data collection commenced initially in case study ‘C’ in late 2003, in case study ‘B’ in early 2004, and in case study ‘A’ in mid-2004. The time taken to collect data varied within each case, dependent on the size of the case, but particularly the differences in time taken by health care professionals to recruit patient participants. Most data collection in each case took place over a 12 week period.

The interview, patient specific documentary and observational data collected from each case are presented figuratively in figures 4.2, 4.3 and 4.4. A summary of the information about respondents interviewed is also given in table 4.2. In addition, non-patient specific documents were also collected from each case, and these are listed according to source in appendix 17. These included blank referral, assessment and case note pro-forma, referral criteria, operational policies and service information leaflets. Other documents were often identified as relevant, and sources of these documents identified by participants. Such documents included cancer network policies and strategies and local policies and strategies.

Table 4.2  Summary of numbers of respondents interviewed for the study

<table>
<thead>
<tr>
<th>Respondent group</th>
<th>Case study site</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
<td>B</td>
</tr>
<tr>
<td>District nursing staff</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>General practitioners</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Allied health professionals</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Key informants</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Specialist palliative care nurses</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Specialist palliative care doctors</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Specialist Allied health professionals</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Patients</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Total number of interviews</td>
<td>14</td>
<td>20</td>
</tr>
</tbody>
</table>
Figure 4.2  Flow chart showing data collected in case study A
Figure 4.3 Flow chart showing data collected from Case study B

...
Figure 4.4 Flow chart showing data collected in case study C.
4.7.1 Issues of data collection

Recruiting professional participants

It became rapidly apparent during recruitment of professional participants, particularly general practitioners, that because of a poor positive response, many more health care professionals would have to be invited to participate than was initially anticipated. During contact telephone calls, most of those declining to participate apologetically cited pressure of work, particularly the work generated by implementation of the new general practitioner contract. Whilst this was particularly apparent in general practitioner recruitment (where only 15% of general practitioners sampled were recruited), it was also an issue in district nurse recruitment (41% of district nurses approached were recruited for the study). Most specialist staff agreed to take part in the study. These issues are discussed further in section 9.5 when assessing the limitations of the study.

Professional participants were therefore invited to participate in the study in stages, with each new phase of recruitment triggered either by a failure to recruit in the previous phase, or a recognition that more data were required. These problems affected the initial plan to recruit groups of health care professionals who worked together. A Microsoft Access™ database was used to monitor study invitations, responses and follow up.

Recruiting patients

As can be seen from figures 4.2, 4.3 and 4.4 patient recruitment fell below the one patient per recruited health care professional envisaged. Patient recruitment was generally discussed directly with the professionals immediately after their interview, with the patient recruitment documentation handed to them at that time. Most informally identified a suitable patient. However, few of these conversations resulted in actual patient recruitment. If no patient were recruited after about 3 or 4 weeks professionals were contacted by telephone and/or by letter (with additional patient recruitment documentation) at least once, usually two or three times, to discuss patient recruitment. Most stated that they did not feel they had an ‘appropriate’ patient for the study at that point in time. Professionals were not
given a time limit for recruitment – indeed one of the patients recruited was identified at least 9 months after the interview with the recruiting professional. It appeared from these conversations that the issue was not that the information was given to patients who subsequently decided not to participate, but that the professionals concerned were reluctant to give patients information about the study. This is discussed further in section 9.5.

A predictable issue in palliative care research is the deterioration or death of patients recruited to the study. This was also an issue in this study. As can be seen from the data collection figures there were a number of patients who consented to be part of the study but who then did not take part. Mostly this was because the health care professional who had recruited them for the study passed on information about their deterioration or death before the planned interview. There was also one occasion when the interview was not commenced after arrival at the house for the interview. It was obvious that the patient was too ill to participate in the interview, and indeed, with the patient’s permission calls were made from the house to the relevant health care professionals to alert them to the patient’s rapidly deteriorating condition. On another occasion the patient had died after the interview was arranged, but this information was not passed on. Again, my background as a palliative care nurse was helpful in dealing with the sensitive situation of unknowingly arriving at the house of someone who had died.

**Accessing health care notes**

The patients who participated in the study were asked for their permission to access health care notes, and all consented to this. Many had home-based notes from the district nursing service, and these were usually accessed at the time of interview. One patient requested a further visit to access these notes after she had discussed this with her district nurses, and this was done.

Whilst a few professionals were happy for me to access their paper or electronic notes, most did not respond to this request. Follow up telephone calls elicited either a refusal to allow me access to the notes despite the patient’s permission, or a request for further consent from the Primary Care Trust’s hierarchy. Whilst such
permissions were followed up and often granted this still affected the number of case notes accessed.

4.8  Data analysis

There were two key themes guiding the approach to data analysis. First, that the conduct of the case study and its analysis was an iterative process, with initial analytical insights informing further data collection, and forcing the theoretical propositions of the study to be revisited (Yin, 1999; Cowley et al., 2001; Yin, 2003a). Second, the analysis of the case study followed a ‘horizontal logic’ (Kohn, 1997). This refers to the focus on analysis within embedded units and cases before across case comparisons are made.

4.8.1  Components of data analysis

Analysis consists of three concurrent flows of activity: data reduction (selecting, focusing, simplifying, abstracting, and transforming the data from transcriptions, documents and field notes); data display (an organised assembly of information which permits conclusion drawing); and conclusion drawing and verification (Miles and Huberman, 1994). These are displayed figuratively in figure 4.5.

![Components of data analysis: Interactive model](Miles and Huberman 1994 p.12)
Case study texts offer little guidance on the most appropriate analytical methods. Yin (2003a) emphasises the use of theoretical propositions and pattern matching, but offers little guidance to facilitate such analyses. Case study methods are notorious for generating large volumes of data, and so a rigorous and systematic approach to ordering and handling this data was essential (Cowley et al., 2001).

A technique which does appear to have utility in facilitating data reduction, data display, data comparison, and conclusion drawing, whilst allowing the above principles of data analysis within case study to be followed is framework analysis (Ritchie and Spencer, 1994; Read et al., 2004). Framework analysis has been successfully used by other case study researchers, and found to facilitate analysis and promote rigour (McDonnell et al., 2000; Woodward et al., 2006). Many of the procedures used in this technique have strong similarities to the matrices and data displays otherwise recommended in case study data analysis to manage and interrogate data, and in pattern matching within and between cases (Miles and Huberman, 1994; Yin, 2004). Framework analysis could be argued to be reductionist because of its reliance on charting data, however, all data analysis essentially reduces data, charting allows this reduction in an overt, observable way.

Framework analysis was developed in the context of conducting applied qualitative research and is described as having seven key features, summarised in figure 4.6.

These key features of framework analysis appear congruent with the case study strategy, particularly the facilitation of between and within case analysis. It was therefore used as the basic approach to analysis in this case study. The approach involves a systematic process of sifting, charting, and sorting material according to key issues and themes following five key stages: familiarisation, identifying a thematic framework, indexing, charging, and mapping and interpretation. The use of these stages in this study is now described.
4.8.2 Familiarisation

As sole researcher, familiarisation with the data was facilitated by conducting all the interviews and collecting all the other data. Interview transcripts were read, and checked against tapes for accuracy. In addition, interviews were listened to several times. Field notes from interviews and observations were also re-read, case note abstractions reviewed, and original documents collected and read.

This process, conducted iteratively throughout the study informed subsequent data collection, and formed the initial basis for indexing. Key ideas and recurrent themes were noted in preparation for identifying a thematic framework (Ritchie and Spencer, 1994).

4.8.3 Creating a thematic framework

An initial thematic framework emerged from the familiarisation stage, where key issues concepts and themes were identified. Ritchie and Spencer (1994) suggest

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**Grounded or generative**: it is heavily based in, and driven by, the original accounts and observations of the people it is about.

**Dynamic**: it is open to change, addition and amendment throughout the analytic process.

**Systematic**: it allows methodical treatment of all similar units of analysis.

**Comprehensive**: it allows a full, and not partial or selective, review of the material collected.

**Enables easy retrieval**: it allows access to, and easy retrieval of, the original textual material.

**Allows between- and within-case analysis**: it enables comparisons between, and associations within cases to be made.

**Accessible to others**: the analytic process, and the interpretations derived from it, can be viewed and judged by people other than the primary analyst.

After Ritchie and Spencer (1994) p.176
that researchers draw upon a priori issues, emergent issues raised by respondents, and analytical themes arising from the patterning of particular views or experiences. In this study the a priori issues were framed by the initial theoretical propositions developed and presented in section 4.2, and further themes developed to both describe elements of data, and to ascribe meaning to data.

The same thematic framework was used in data analysis from each case. It is recommended that a common index is used as this helps to identify both common and divergent themes (Ritchie and Spencer, 1994). The framework changed and developed during the study, and data were re-visited continually and assessed against the changed framework. A copy of the final framework developed is found in appendix 18.

4.8.4 Indexing

Indexing refers to the process whereby the thematic framework or index is systematically applied to the data in its textual form, and changes made to it to reflect data collected (Ritchie and Spencer, 1994). In this study, creating the thematic framework and indexing was facilitated by use of the Nvivo 2.0™ computer programme, a type of computer aided qualitative data analysis software (Richards, 1999). The interview transcripts and field notes, field notes from observational data, and either electronic copies of documents where available, or summaries of documents were imported into Nvivo 2.0™. These textual elements were created into ‘sets’ for each case study, and attributes given to each document to identify sub-units of analysis (for example district nurses, or specialist staff) so that the data could be interrogated for each case study, and sub unit of analysis within the study, using the same thematic framework. The programme was then used to assign elements of the index to segments of text. These sections could then be easily retrieved for charting, or the programme used to interrogate juxtapositions of elements of the index. An example of a part of a coded interview is found in appendix 19.
4.8.5 Charting

Charting refers to the process whereby data are lifted from their original context and rearranged according to the appropriate thematic reference (Ritchie and Spencer, 1994). Charts were developed for each major thematic grouping for each case study to facilitate within case analysis. Within each chart respondents were grouped according to their professional background/employment to facilitate analysis by sub-unit. The rows within each chart represented individual respondents, observations or documents, the columns the themes from the thematic framework which contributed to the overall subject area of the chart. An example of part of a chart is found in appendix 20.

Construction of such charts is a form of analytical technique similar to ‘word tables’ described by Yin (2003a p.134) where he suggests that tables can display data from individual cases according to some uniform framework. Such tabular display can assist cross-case analysis by allowing easy recognition of cross-case patterns.

4.8.6 Mapping and interpretation

Mapping and interpretation is where key characteristics of the data are pulled together, and the data set as a whole is mapped and interpreted (Ritchie and Spencer, 1994). This consists of comparing and contrasting perceptions and accounts and searching for patterns and connections. A key strategy was to focus attention on relevant data using the theoretical propositions developed and refined during the indexing, charting and interpretation processes. This is a form of pattern matching, which compares an empirically based pattern with a predicted one (Trochim, 1989).

Techniques suggested by Eisenhardt (1989) were used to facilitate cross case analysis. First, the cases (and their associated charts) were paired in different combinations to examine similarities and differences between the cases. Second, the data was divided by source and compared across cases. Third, categories or propositions were selected and within group similarities coupled with inter-group differences were sought. This process resulted in three main themes emerging...
from the data which were common to each case. These themes are reflected in
the way the finding chapters are structured, and therefore the structure of the
findings chapters relates directly to the patterns which emerged from the cross-
case analysis.

4.9 Methodological rigour

There is an ongoing debate, particularly between researchers from qualitative
traditions, about the best ways of both ensuring high quality research during the
research process, and also evaluating the quality of the research product (Morse
et al., 2002). Whilst some suggest that qualitative research requires separate
quality criteria from quantitative research in recognition of different epistemological
backgrounds, others argue that the muddle caused by different authors
promulgating different criteria has done research a disservice (Lincoln and Guba,
1985; Morse et al., 2002; Rolfe, 2006). Three positions have been identified: those
who want qualitative research to be judged by the same criteria as quantitative
research, those who believe that a different set of criteria is required, and those
who question the appropriateness of any set criteria (Rolfe, 2006). In addition,
there are confusions caused by those who argue that a study should be judged
post-hoc for quality, and those who argue for verification strategies during the
study itself (Sandelowski, 1993; Popay et al., 1998; Morse et al., 2002). There are
therefore no clear, unanimously agreed criteria for judging qualitative research, nor
tactics for verifying the research process.

This confusion becomes more acute in case study research, where data collection
can encompass both qualitative and quantitative methods, where authors position
case study within different paradigms, and where the particular techniques of case
study research may demand particular ways of ensuring quality (Stake, 1995;
Darke et al., 1998; Yin, 1999; Robson, 2002; Yin, 2003a).

There are few authors who have specifically addressed the issue of ensuring case
study research is rigorous. Yin (2003a) suggests an approach based on the four
tests commonly used to establish the quality of any empirical social research
(construct validity, internal validity, external validity and reliability). Whilst Yin
positions himself within a positivist paradigm, such an approach would also be
recognised by those qualitative researchers who argue that the broad and abstract concepts of reliability and validity can be applied to all research because the goal of finding plausible and credible outcome explanations is central to all research (Morse et al., 2002). It is the tactics used to ensure quality that are important, not necessarily the label given to them. Within case study both the ‘quantitative’ criteria suggested by Yin, and ‘qualitative’ criteria may be appropriate (Riege, 2003). However, a closer examination of the criteria proposed by Riege (2003) reveals that the actual verification strategies are similar. Comparable verification strategies for case study research and assessing case study reports are also suggested by other authors (Darke et al., 1998; Yin, 1999; Lincoln and Guba, 2002).

For this research, the broad approach suggested by Yin (2003a) was followed, augmented by other case study specific recommendations (Darke et al., 1998; Yin, 1999; Lincoln and Guba, 2002; Riege, 2003). This recognised both that this case study strategy mostly followed the ideas of Yin, and that particular tactics to promote quality within case study strategies need to be followed. The strategies used in this study are presented in table 4.3. Note that tactics for internal validity are not presented, as these are only a concern for causal (or explanatory) case studies, not where the aim is descriptive, as in this case study (Yin, 2003a). However, the tactics for the similar ‘qualitative’ criterion of credibility are presented and were used (Riege, 2003).

4.10 Summary

This chapter presents how the study was conducted. It demonstrates that a case study strategy was an appropriate research choice, that it was conducted with rigour, and with attention to the sensitive nature of the subject in the sampling, data collection, and analysis of the data. The strengths and limitations of the research and its design are discussed in chapter 9.

The next chapter presents information about the context of the cases studied.
### Table 4.3 Case study tactics for the four design tests
(After Yin 2003a p.34)

<table>
<thead>
<tr>
<th>Test</th>
<th>Case study tactics used in this research</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Construct validity</strong></td>
<td>Establishing correct operational measures for the concepts being studied (Yin, 2003a)</td>
</tr>
<tr>
<td><strong>Confirmability</strong> (Riege, 2003)</td>
<td>Whether the interpretation of data is drawn in a logical and unprejudiced manner</td>
</tr>
<tr>
<td></td>
<td>• Use of multiple sources of evidence (observation, documentary evidence, interviews with different professionals and patients)</td>
</tr>
<tr>
<td></td>
<td>• Established chain of evidence using Nvivo™ to track data and charting techniques, similar to a confirmability audit examining the data, findings, interpretation and recommendations</td>
</tr>
<tr>
<td></td>
<td>• Explicit and detailed description of research methods and procedures given</td>
</tr>
<tr>
<td><strong>Credibility</strong> (Riege, 2003)</td>
<td>To demonstrate that the inquiry was carried out in a way which ensures credibility</td>
</tr>
<tr>
<td></td>
<td>• Peer debriefing carried out with members of research advisory group, including fellow researchers, and palliative care professionals. Supervision, including reading of transcripts, independently identifying key themes, critical comment on interpretations. Presentation of findings to pertinent audiences</td>
</tr>
<tr>
<td></td>
<td>• Attempt to give meaningful descriptions of themes with ample data extracts to support themes</td>
</tr>
<tr>
<td></td>
<td>• Systematically relating concepts through use of theoretical propositions</td>
</tr>
<tr>
<td><strong>External validity</strong></td>
<td>Establishing the domain to which a study’s findings can be generalised (Yin, 2003a)</td>
</tr>
<tr>
<td><strong>Transferability</strong> (Riege, 2003)</td>
<td>Similar or different findings of a phenomenon amongst similar or different respondents or organisations i.e. achieving analytical generalisation.</td>
</tr>
<tr>
<td></td>
<td>• Use of replication logic, where the same theoretical propositions are supported in more than one case study site</td>
</tr>
<tr>
<td></td>
<td>• Use of ‘thick’ description of findings for readers to assess potential transferability to their own settings</td>
</tr>
<tr>
<td><strong>Reliability</strong></td>
<td>Demonstrating that the operations of a study, such as the data collection procedures, can be repeated, with the same results (Yin, 2003a)</td>
</tr>
<tr>
<td><strong>Dependability</strong></td>
<td>To show indications of stability and consistency in the process of inquiry (Riege, 2003)</td>
</tr>
<tr>
<td></td>
<td>• Case study protocol and case study database developed (use of Access to track interview invitations and responses, Nvivo™ to store and collate raw data, and charting to reduce data whilst maintaining source information)</td>
</tr>
<tr>
<td></td>
<td>• Use of clear research questions and theoretical propositions congruent with the features of the study design</td>
</tr>
<tr>
<td></td>
<td>• Verbatim recordings of interview data</td>
</tr>
</tbody>
</table>
Chapter five

The cases and their contexts
5.1 Introduction

Case study research can be presented in a number of different ways. It is common for each case to be presented separately, with cross case issues addressed after case presentations. However, another acknowledged form of presentation is to devote each chapter to a separate cross case issue, with information from the separate cases dispersed throughout each chapter. Summary information about the cases can be presented as abbreviated vignettes (Burgess et al., 1994; Yin, 2003a). This format is followed in this thesis, where chapters 6, 7 and 8 present the main findings of the study about referral practices within community palliative care as cross case analyses. This chapter describes the cases in summary form as context for the cross case analyses. This form of presentation was chosen as the best fit when the cross case analysis revealed similar issues influencing referrals across the cases.

The Primary Care Trusts (cases) within which the referral of palliative care patients took place are described in terms of their geographies, estimated palliative care needs, and organisation and provision of palliative care. The aim of this section is to highlight differences and similarities between the cases in the four areas described above. Referral practices described in chapters 6, 7 and 8 then can be either related to the particular contexts of the cases, or shown to operate across all the different contexts.

A population based needs assessment for palliative care is recommended as a method of assessing aggregate palliative care needs (Tebbit, 2004). This method takes account of information about population levels, age structure, ethnicity and deprivation as well as current palliative care provision. It provides an accepted approach to comparing the demographic, epidemiological and socio-economic characteristics of areas, and deriving a measure of comparative palliative care need from this. This comparison of palliative care needs was completed using data from the three case study areas. In the interests of brevity the full assessment is found in appendix 21, including information about data sources, but elements from this assessment are incorporated into the case study vignettes presented here. Where data sources are not referenced in appendix 21 they are cited separately here.
5.2 The geography and demography of the Primary Care Trusts

The Primary Care Trusts selected were all in the North West of England. Two were within the same Health Authority and cancer network area (data was collected prior to the recent mergers of Health Authorities and Primary Care Trusts), but the third fell within a different Health Authority and cancer network in the region. Where numbers or percentages (for example of population sizes) are given they are rounded to attempt to conceal the identity of the Primary Care Trusts.

Case study A

The Primary Care Trust forming case study site A served the population of two geographically close towns, each with their own distinct identity. Whilst the towns have been administered together in both health and local council terms for most of the preceding three decades, there was a distinct sense of individual identity and separateness between them. The Primary Care Trust incorporated some small villages on the outskirts of the two towns, but the population served generally lived in urban and suburban estates surrounding the town centres. The population of just under 120,000 made this the smallest case study site in terms of population served. The area was co-terminus with the local authority area.

The towns had a significant industrial heritage, and indeed the manufacturing industry was still the sector employing the largest numbers of the workforce within the area. The area had a younger population than the national average, with only 18% of the population over 60 years (England 21%) although the declining birth rate and generally shrinking population in the area were bringing the area closer to the national average age profile. The number of those living in a single person household was 27%, compared to the England average of 30%. Thirteen percent of pensioners lived a single person household, close to the England average of 14%. Of those who were over 60 years, 44% were male, dropping to 37% of over 75 year olds. These proportions were very similar to those found in the other two sites.
The area was generally economically deprived. Fifty percent of the wards within the Primary Care Trust area were in the top 10% of deprived wards in England, although it did have one ward in the bottom 30% of most deprived wards. The majority (99%) of the local population were white, with 84% describing themselves as Christian.

**Case study B**

The Primary Care Trust forming case study site B served one of the largest town populations in the North West, with a population of over 260,000, more than twice the number of case study A. The population was principally focused within the urban and suburban areas of the town, but a significant minority of the population lived in dispersed villages around the borough. The area was co-terminus with the local authority area. The town had an industrial heritage, but this industry had been mainly supplanted, with a more mixed employment profile. The area had the oldest age profile of the three Primary Care Trusts, with 20% of the population over 60 years, close to the national average. Thirty one percent of the total population lived in a single person household, 15% of the pensioner population. Forty four percent of those over 60 years were men, and 38% of those over 75 years.

In comparison with the two other sites this area was least deprived, but did contain significantly deprived wards. Thirty three percent of wards were in the top 10% of deprived wards in England, none in the bottom 30%. The ethnic mix of the local population was more varied, with 89% of the population being white and a substantial Asian minority (9%) population. Seventy five percent of the population described themselves as Christian, and 7% as Muslim.

**Case study C**

The primary care trust forming case study site C served an urban area in the North West with a population just under 140,000. The population lived entirely within this urban area. Areas of dense population were interspersed with sites for both large employers, and smaller employers in industrial and other units. The area was not co-terminus with the local authority area, and formed one part of a large city
council area. The area had a large transient population with a younger than average age profile, with only 14% of the population being over 60 years. There were high numbers living in single person households, 40% compared to the England average of 30%. However the number of pensioners in single person households was 13%, close to the England average. Forty five percent of those over 60 years were male, and 37% of those over 75 years.

The vast majority of the wards in the area had high levels of deprivation, with 80% of wards in the top 10% of deprived wards in England, and none in the bottom 30%. There was a significant ethnic minority population, with 69% of the population describing themselves as white, 15% as Asian, and 9% as black, mainly from Afro-Caribbean communities.

5.3 Potential need for palliative care provision

Whilst is argued that palliative care need must also take account of the demographic information presented above, this section looks specifically at the potential health care needs of those within the case study sites based on estimates relating to number of deaths, a technique first used by Higginson (1997), and then adapted in the population based health care assessment (Tebbit, 2004).

Case study A

Case study A had a rate of death from cancer which was much higher than either of the other two sites, and which was also considerably greater than the England and Wales average.

An average of the 2002 – 2004 figures showed nearly 1 200 deaths per annum within the Primary Care Trust, with 28% (nearly 330) being from cancer. Whilst the all deaths per 100 000 population figure of 997 was below the England and Wales average of 1034, the cancer deaths per 100 000 population of 275 was above the England and Wales average of 256. These figures indicate that for some reason, the number of those dying from cancer was higher than would be expected, but this trend was not reflected in the overall mortality statistics.
Case study B

Data from 2002 showed that there were just over 2,700 deaths in the Primary Care Trust area that year, with 24% (just over 650) being from cancer. The all deaths per 100,000 population figure of nearly 1050 was over the England and Wales figure of 1034, with the cancer deaths per 100,000 of just over 250 being close to the England and Wales average of 256.

Case study C

Data from 2001 showed that there were 1360 deaths that year within the Primary Care Trust with nearly 320 (23%) being from cancer. The all deaths per 100,000 population figure of nearly 980 was the lowest of all three Primary Care Trust areas, as was the cancer deaths per 100,000 figure of nearly 230. These were also well below the England and Wales averages of 1034 and 256 respectively, and probably reflect the younger age structure of the population served.

An estimation of the prevalence of problems and symptoms in people with cancer and progressive non-malignant disease within each case study site in the last year of life was made and is presented in the full needs assessment in appendix 21. These figures are proportional to the total numbers dying in each case study site from cancer and other progressive non-malignant diseases.

5.4 The organisation and provision of palliative care services within the case study sites

Case study A

Case study A had the smallest population of the sites studied, and this was reflected in the size and range of the services it provided.

There were 67 General Practitioners serving the Primary Care Trust area. In the most southerly town (South Town) of the two served they were mostly in 6 large health centres, with only one single handed general practitioner. Many of these large surgeries were close to the town centre, causing some access difficulties
from outlying areas. There were 10 smaller practices serving North Town – with 4 single handed general practitioners. Eighty four percent of the general practitioners qualified in the UK (data from www.primary-care-db.org.uk). There were 12 district nursing teams serving the area, each assigned a general practice(s). These teams varied in size from the largest with 10 staff members to the smallest with three. Overall there were 13 district nursing sisters employed, with 58 support staff, the majority of these being qualified nurses. Not all of these staff were full time.

The general practitioners in this area, South Town in particular, had a reputation for innovation. Some have been at the forefront of new initiatives in the way primary care services are developed. The Primary Care Trust has been involved in the piloting or initial waves of some primary care initiatives and at the time of this study were just embarking on a new way of following through, tracking and supporting cancer patients through their journey. The area was also an early adopter of the Gold Standards Framework, with all of the practices in South Town, and most in North Town involved in this work for the past few years or more.

There was a general sense that these initiatives were driven by a few motivated individuals – but that the Primary Care Trust management was sluggish and remote. Particularly the district nurses interviewed expressed discontent with management citing poor lines of communication, disinterest in their concerns, and tardiness in addressing some significant staff shortages across the trust:

‘I think we’ve had poor leadership for about, I don’t know 2 or 3 years, um, short of staff, they’ve not replaced staff when they’ve gone we’ve been running, not particularly my team, but we’re only a small team, and then we’ve had to help other teams out, um, morale is really, really low, In District Nursing, we feel as though we’re the bottom of the pile, And I think that’s just poor leadership, and it’s such a shame it used to be really good, but not any more.’ (A/DN4)

There was also a distinct sense of difference between the staff based in South Town and those in North Town which they emphasised was also felt by the populations of the two areas. This was particularly commented on with reference to access to the area’s hospice, based in South Town, and which professionals felt
North Town residents were less likely to access because of the geographical difficulties of travelling there.

Specialist palliative care provision in case study site A was in a significant state of flux at the time of the study – a fact commented upon by most interviewees. The area has a small, developing Hospice which provided in-patient beds, day hospice services and some newly developed out patient clinics. The hospice had only within the last few years changed its registration from a nursing home to a hospice, and this was felt illustrative by some both of its origins, and the development it was striving for. It had also only recently appointed its own medical officer, a development which was perceived positively by most.

Most of the specialist palliative care professionals in the area had a base at the hospice, irrespective of funding or employer. The Primary Care Trust area shared a Consultant in Palliative Medicine with a neighbouring Primary Care Trust. The consultant also had a remit within the other areas hospice, and acute trust which served both areas. This was an appointment made less than a year ago, so the role was developing. However, the consultant was away for most of the study period. The 0.5 WTE available to the area population was over the 0.23 WTE which would be suggested by the calculations of the needs assessment in appendix 21. The hospice was the base for a weekly multi-disciplinary palliative care meeting, chaired by the consultant, to which all palliative care professionals were invited and also generalist professionals if one of their patients were discussed, or as a learning exercise. The focus of this meeting was to discuss patients ‘known’ to the hospice, whether as an in-patient or day patient.

There were some significant changes within the Community Macmillan Team during the study period, with all the (three) members of the team having left within the last six months, such that there were only vacant posts for most of the study period. Had they all been in post, the 3.0 WTE funded was close to the 2.7 WTE suggested by the size of population. The feedback from most interviewees was that they perceived significant problems within the old team in terms of their low workload, poor responses to referrals, inadequate training and educational opportunities and attitudes to other staff. The general picture was that whilst the retiring North Town nurse was respected, the South Town staff that left to pursue
other avenues had lost the confidence of many of the staff with whom they worked. One new appointment was made to the team during the study period.

The final specialist palliative care services provided within the area were the hospice at home service and Marie Curie nursing services. The hospice at home service had been set up three years previously using New Opportunities Fund monies, and was managed jointly with the Marie Curie service, with much overlap between staff and patients. Both services aimed to provide intensive home nursing care at the end of life, with Marie Curie service generally being used to provide nursing care overnight, and hospice at home for prolonged periods during the day. Whilst this was generally positively evaluated by staff, the nurse co-ordinating the service had also taken on another role, and there was a feeling that the service was losing its momentum and its funding was at risk. It had also been less used than predicted, with the total numbers of referrals for the first two years of its operation standing at 64 for Hospice at Home, and 12 for Marie Curie. Eighty percent of these referrals came from the district nursing service.

The indications for all these general and specialist services were that they would receive referrals from any source.

All of these elements led to a feeling within the case study area that specialist palliative care provision was unstable, and significant developments were required. This led to an emphasis on generalist skills and involvement in specialist palliative care.

Of the three case study sites, case study A appeared to achieve the highest numbers of home deaths (for patients dying from cancer), although 23% was still below the national average of 25%. Forty eight percent died in hospital, close to the national average of 47%. The highest proportion of any case study site (23%) died in a hospice, above the national average of 17%. Only 4% died in a care home, below the national average of 12%, and this perhaps reflects the paucity of care homes in the area, and also the recent nursing home registration of the hospice which had influenced its thinking regarding actively admitting people for terminal care.
Case study B

Case study B served the largest population of the three sites studied, and this was reflected in the size and breadth of the services provided.

There were 148 general practitioners serving the area across 57 surgeries. Given the geographical spread of the area, it was not unusual for these practices to operate from both a main and branch surgery. There were 14 single handed general practitioners, and also a considerable number of small practices with two general practitioners. As single handed general practitioners are more likely to wish to hand over palliative care to specialists this may be an important issue (Burt et al., 2006). A quarter of the general practitioners employed qualified outside the UK (www.primary-care-db.org.uk). There was no available listing of district nursing teams, but each practice or group of practices had a district nursing team attached led by one of 21 district nursing sisters.

Unlike in case study A, where staff made reference both to the national profile enjoyed by the Primary Care Trust, and the lack of adequate management, the management or organisation of the primary care trust was rarely mentioned by interviewees in case study B. There was limited awareness by some staff that improvements in palliative care was a stated objective of the district nursing service, and recognition that monies had been obtained via cancer networks and the new opportunities fund to support palliative care education and provision, but generally the feeling was of staff just getting on with their jobs irrespective of what was happening within the Primary Care Trust:

“What sort of priority would you say that ‘B’ PCT actually gives to palliative care and the provision of palliative care services?

‘I don’t know really. I don’t know how to answer that. In terms of, I don’t know. I couldn’t answer that to be honest with you. It’s something that I personally see as a priority in my caseload, but I suppose if I didn’t see it as a priority then, so for me it’s quite high. So whether the PCT it was a priority for them, it would still be a high priority for me, do you know what I mean. So, I just do what I have to do for the patients, so I don’t know really.’ (B/DN3)
Possibly some of the reason for the lack of comment on the Primary Care Trust involvement in palliative care issues was that many recognised the hospice as a driving force. The hospice serving area B was centrally located, providing in-patient care, day hospice, consultant clinics, hospice at home service and a base for the community Macmillan nursing service (two full time, one seconded part-time from the district nursing service, employed by the acute trust) and other specialist allied health professionals. Its services were well established and provided in modern, purpose-built accommodation. The available figures for day hospice care showed that in 2001/2 211 people attended day care, and in 2002/3 150 attended. One hundred and forty nine people attended outpatient clinics in 2000/1, increasing to 222 the following year. No figures were available for other services. The hospice services (day hospice, out-patient clinics, hospice at home, community Macmillan nursing services) shared a referral form which indicated that it had to be countersigned by a medical practitioner, however whilst this appeared to take place for the services based at the hospice, more informal mechanisms without such a signature were reported for the hospice at home and community Macmillan teams.

The lynch-pins of the services provided appeared to be the consultants in palliative medicine who by virtue of their work both within and outside of the hospice were central to the way the services operated. There were 2.0 WTE consultants serving the area, above the 0.52 WTE suggested for the size of the population. This was in contrast to the 2.5 WTE community Macmillan nurses, below the 6 WTE suggested for the size of the population. The hospice also acted as the base for the local palliative care strategy group, which had a wide membership across specialist and generalist disciplines and incorporated management and commissioning staff. It acted as a focus for many of the issues and initiatives within the area. Many of the representatives on this group also sat on relevant Cancer Network committees, again reinforcing its central influencing position.

The importance of the hospice to the way specialist palliative care was provided within case study B was emphasised by many respondents. Because of the range of services it provided staff working with the hospice were aware of most patients with cancer related palliative care needs in the area.
Case study site B was also in the process of winding down a three year New Opportunities Funded project aimed at widening access to cancer and palliative care services for those from deprived areas or ethnic minority groups. Feedback on the effectiveness of this service was mixed, as it appeared to have had a difficult inception with staffing problems and unclear objectives. Rapid access to benefits advice and allied health professional input was appreciated.

Twenty two percent of those dying from cancer in the case study site died at home, 49% in hospital, 20% in the hospice and 8% in a care home. As with case study A, the numbers dying in a hospice were above the national average.

Case study C

This Primary Care Trust served a moderately sized urban population. Because of its lack of distinct population or geographic borders, some of the services the population accessed were outside the Primary Care Trust borders.

There were 105 general practitioners serving the area in 43 practices. Sixteen of these practices contained single handed general practitioners, with a further 11 small practices served by two general practitioners. The area served was ethnically mixed, and 16% of the general practitioners employed qualified outside the UK (www.primary-care-db.org.uk). There were 22 district nursing sisters, and 72 district nursing staff in total. Each team was attached to a general practice or practices. Because of the relatively high number of very small general practices, it was common for the district nurses not to be based in the surgeries of many general practitioners with whom they worked.

The organisation of the Primary Care Trust and its impact on palliative care services was rarely directly mentioned by respondents in the study. The issue which appeared to most concern respondents was their ability to meet the overwhelming needs of the deprived population. There was a sense that general services were under resourced, compounded by a high staff turnover and vacancy rate. Services were therefore perceived as extremely stretched, struggling to cope with the basics of care. Blame for this did not seem to be laid at the Primary Care
Trust’s door (as in case study A), but because of the area within which they worked, which was widely perceived as unattractive to staff recruitment.

Specialist palliative care within the primary care trust area consisted only of the community Macmillan nursing team (three nurses, close to the 3.2 WTE suggested by the size of the population), supported by a small amount of specialist occupational therapy time. They were the only team who provided detailed data about patients. In 2001/2 162 patients received care (new and existing patients), resulting in 879 contacts – an average of 5 per patient, and in 2002/3 128 patients, with 816 contacts, an average of 6 per patient. Over this two year period, 66% of patients were white, 10% from black and ethnic minority populations, and 23% had no ethnicity recorded. It is hard to compare this with the population statistics because of the high proportion of those whose ethnicity is not recorded, but if these are disregarded then the percentage of those from black and ethnic populations accessing their care appeared low (population percentage 24%). Seventy seven percent of the referrals over that two year period originated from a community source, with general practitioners (34%), and district nurses and other community nursing staff (39%) being the most frequent referrers. Referrals were accepted from any source.

Other specialist palliative care, such as hospice care, was accessed outside the area. This was perceived as a difficult issue by some staff. The issues were related to travelling and access time for those who often did not have access to their own transport, and also whether the services provided were suitable for the ethnically diverse population, as they were provided in a leafy suburb:

‘Is, is that an issue for, for [case study C] that the hospice is not within the bounds of the PCT?
A: Yes...Yes. An issue for [case study C] not just in that geographical case, the hospice but also for patients of [case study C] that may not want to access, no, may not want to be in a hospice environment err, and for the diverse communities that we’ve got here and the different cultural needs and expectations of patients and the high levels of deprivation...poverty and the ability to travel such a distance and, you know, communities not being able to, to visit patients that are so far away because...’ (C/KI2)
The area was also not served by other agencies such as Marie Curie care. Whilst this service had been accessed in the past, the frequent complaints about not being able to easily access carers, and about carers being reluctant to provide care in a deprived urban area had led to dissatisfaction with the service, and the funding was currently on hold. As the sole provider of specialist palliative care within the area, the Macmillan nursing service therefore found itself involved not just with care provision, but in providing a lead role within the Primary Care Trust (one of the nurses was also the lead cancer nurse), in attending local palliative care meetings, and in providing leadership – roles which were shared amongst other staff in the other case study sites. The nurses strongly valued the autonomy this gave them as nurses, and discussed reluctance to want to move to any other model of care:

‘But I don’t know, I don’t think I would like somebody else making decisions like that. About whether I could cope or whether I was able, you know, able to take on new referrals or not discharge them or whatever. I don’t like, I certainly wouldn’t like a medical bod doing that, because it’s a different perspective totally. I am quite happy with the system we have got.’ (C/SN1)

Despite the concerns they expressed about their geographical and cultural distance from a hospice, they did not see the provision of in-patient hospice care as an aim for the area – looking instead to develop community based models of care such as a hospice at home service. Progress towards these aims appeared slow, and although not recognised by the specialist nurses, may have been impeded by a lack of a medical voice supporting these aims.

Of all the case study sites, case C achieved the lowest percentage of those dying at home (20%), and also the lowest percentage of those dying in a hospice (14%). These are both below the national average. Over half of those dying from cancer in the area died in hospital (53%) which may reflect both the location of a major teaching hospital within the Primary Care Trust area, and also the lack of a local hospice.
Benchmarking approach

The final step in the population based needs assessment for palliative care is to compare need – in this case between the three primary care trusts studied (Tebbit, 2004). The protocol suggested for this is to take the cancer deaths per 100,000, and ascribe an index value for that relative to the highest rate for any primary care trust. This is modified by a deprivation modifier which is calculated from the average of ward ranks for all local authority populations. The Primary Care Trust with the least need is ascribed an index value of 100 and the relative index value of the other primary care trusts calculated from this (Tebbit 2004). Table 5.1 shows these calculations for the three primary care trusts studied – indicating that case study C has the lowest need and case study A the highest according to these criteria.

Table 5.1 Index of comparative need for the three case study sites

<table>
<thead>
<tr>
<th>PCT</th>
<th>Cancer deaths per 100 000</th>
<th>Index value</th>
<th>Deprivation modifier</th>
<th>Modified index value</th>
<th>PCT need index value</th>
<th>Effect on resource needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>275</td>
<td>94.3</td>
<td>1.94</td>
<td>182.9</td>
<td>117</td>
<td>+ 17</td>
</tr>
<tr>
<td>B</td>
<td>251</td>
<td>96.3</td>
<td>1.86</td>
<td>179.1</td>
<td>115</td>
<td>+ 15</td>
</tr>
<tr>
<td>C</td>
<td>229</td>
<td>78.8</td>
<td>1.99</td>
<td>156.8</td>
<td>100</td>
<td>-</td>
</tr>
</tbody>
</table>

(Data source: index value data from National Centre for Health Outcomes Development [www.nchod.nhs.uk](http://www.nchod.nhs.uk) relative to the highest rate for any local authority in the country. C = city wide data. Effect on resource needed is relative to the lowest modified index value (C) Calculations based on Tebbit 2004).

5.5 Summary

This chapter presents brief vignettes of the cases as context for the cross-case analysis which follows. These reveal differences between the cases in their contexts, geography, demography, the way that specialist palliative care is organised, the scale of provision of services, and the opinions of those working within them about the organisation and management of services. The cases were chosen partly because of these differences in the way specialist palliative care services operated, on the basis of theoretical replication – that there would be
differences in influences on referrals because of these different patterns of provision.

For ease of reference table 5.2 presents a summary of the specialist palliative care services provided within each case. General palliative care services (district nurses, general practitioners, allied health professionals etc.) were available within each case.

The study presented here examines referrals within the cases. These referrals are therefore primarily between the specialist services highlighted above and those providing general palliative care, mainly general practitioners and district nurses. The influences on these referrals within these cases are now presented in the next three chapters.

**Table 5.2** Summary of specialist palliative care provision within the cases studied

<table>
<thead>
<tr>
<th>Service provided</th>
<th>Case study A</th>
<th>Case study B</th>
<th>Case study C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community palliative care nurse(s) (Community Macmillan nurse)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Specialist allied health professional(s)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Consultant(s) in Palliative Medicine</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Day hospice</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Palliative care out patient clinics</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Hospice at home service</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Marie Curie service</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Cancer co-ordinating service</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
Chapter six

Making referrals within community palliative care services
6.1 Introduction to the research findings

The essential findings of this thesis are that patients’ access to community palliative care services was not solely based on an assessment of their needs, preferences, or ability to benefit from services provided. Whilst these issues did have an impact on access, whether services are proffered, accepted, or continued appeared dependent on a much more complex interplay of factors, particularly the way professionals providing care perceived their own role in providing palliative care to patients and carers, how they perceived the role of other professionals and the services within which they work, and their assessment of the value added by the referral. These professional and inter-professional factors appeared critical to the complex decisions made about palliative care provision to individual patients and their carers.

The three findings chapters are structured to reflect the three main issues which emerged from the analysis: describing referral processes within the cases, examining how professionals’ perceptions of their own roles in palliative care affected referral practices, and how professionals’ work with others affected referrals.

This chapter sets the scene for the discussion of these personal, professional and inter-professional factors by describing the way health care professionals explained the referral making processes within their case study areas. The reasons professionals gave for making referrals to community palliative care services are discussed, and issues directly related to this process described: whether they felt referrals were appropriate, the use of referral criteria; and issues relating to the timing of referrals.

As discussed in the previous chapter, this chapter, and the two that follow, present the findings from the cross-case analysis. This allows the central themes found across the cases to be drawn out and discussed, however particular within-case issues are highlighted where the cases differed.
6.2 Reasons for referral to community palliative care services

Most of the community palliative care services studied were referral driven, with the exception of general practitioners, who generally had been involved in caring for the patient and family before palliative care was required. Other services such as district nursing, specialist palliative care nursing, or any form of hospice care required a referral to be actively made, or some other form of information transfer about patients. Referrals were the driving force behind the movement of patients ‘through the system’, and without them most services had no knowledge of patients who may benefit from their care.

A key issue in the referral making process was that the focus of the referral was on the ‘reason’ given for the referral of a patient (or their carers) to a particular service at that moment in time. Such reasons for referral appeared to be the way services defined the rationale for the referral and affected how they framed their response to the referral. These reasons were discussed primarily in the interviews conducted, but were also apparent from the observation of meetings, and documentary analysis of referral and assessment proforma, referral criteria, and case notes.

These given ‘reasons for referrals’ were primarily framed by reference to a bio-psycho-social model of care, focusing on physical, psychological and social reasons for referral to particular palliative care services. Whilst these reasons were reflected in the way referral proforma were constructed, their use in practice was principally illustrated by the interview and observational data. What was very clear from an initial appraisal of these data was that such physical, psychological and social reasons for referral were not equally discussed, as illustrated by an examination of the number of paragraphs assigned to these three reason codes.

The indexing of the interview and observational data included the use of descriptive codes applied whenever the reasons for a referral being made were discussed. Whilst the absolute numbers of segments of text coded is dependent on a number of factors such as the length and number of interviews, and the way the discourse within the interview progressed, the way the codes were used may
be indicative of the relative importance to professionals of such reasons for referral. The use of these codes within the study is displayed in table 6.1.

Table 6.1 Use of the reasons for referral code within the thematic framework

<table>
<thead>
<tr>
<th>Code</th>
<th>Case study site</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
<td>B</td>
</tr>
<tr>
<td>Social reasons</td>
<td>17</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>(27%)*</td>
<td>(17%)</td>
</tr>
<tr>
<td>Psychological reasons</td>
<td>6</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>(10%)</td>
<td>(33%)</td>
</tr>
<tr>
<td>Physical reasons</td>
<td>38</td>
<td>53</td>
</tr>
<tr>
<td></td>
<td>(62%)</td>
<td>(50%)</td>
</tr>
<tr>
<td>Total number of coded segments in the ‘Reasons for referral’ branch</td>
<td>61</td>
<td>106</td>
</tr>
<tr>
<td>Total number of coded segments in each case study</td>
<td>1263</td>
<td>2306</td>
</tr>
</tbody>
</table>

*Percentages given are of the total number of coded segments for the reasons for referral branch of the thematic framework within that case study site.

The use of the codes displayed in table 6.1 illustrates the dominance of discussion of physical reasons for referral within the data. There were differences apparent between the cases, which whilst they may be just an artefact of the way the codes were used, seemed to reflect the shortages of Community Macmillan Nurses in case study A, which appeared to limit the discussions of referrals to this service, a service which was heavily used in the other cases for the provision of psychological care. The preponderance of discussion of physical and psychological reasons for referral appears to mirror the reasons given for referral discussed in section 2.3.4.

The social, psychological and physical reasons given for referral to these services are now discussed in more detail.

6.2.1 Social reasons for referral to community palliative care services

Social reasons for referrals were most often described either when making referrals to day hospice services, or to pass care not seen as ‘nursing’ to social services care staff.
Referrals to day hospice services were considered to address issues of perceived social isolation in patients, to enable patients to meet others in similar situations, and to support carers. Particularly in case study A, where the provision of specialist palliative care services within the day hospice was embryonic, such reasons appeared to be the prime motivator for referrals into this service:

‘Well the criteria is quite lax, open, fluid really. It’s like a little bit of a social club really, so if anybody is feeling a little bit socially isolated then that would be fine, if there’s carer problems then that would be fine as well, if they want to maybe access some holistic therapies that would be another reason, but none of them particularly specialist reasons really.’ (A/SN4)

However, even in case study B, where the hospice was acknowledged as a provider of specialist medical care, the day hospice was also seen as a provider of social care, although it also served as an introduction to the hospice, which could work to facilitate future care:

‘If the patients are a bit socially isolated then sometimes it’s a good means of them getting out, a change of scene, and mixing with other people. A bit of pampering as well I would say, they do aromatherapy and have their hair done and manicures, that kind of thing. But the other good thing about it is that they are all seen by the consultant when they go to the day hospice, so if you have got anyone who is experiencing problems, it is a good way to tap into that as well.’ (B/DN3)

As discussed in chapter 8, this use of other services to access an alternative source of expertise if required for the future was a common strategy. A referral for ostensibly ‘social’ reasons was a legitimate way of accessing such expertise, and anticipating future care needs, without overtly criticising or confronting a fellow professional.

Access to the out-of-area day hospice was rarely mentioned by health care professionals in case study C. Certainly, many professionals were concerned about referrals to the out of area hospice because of the travelling involved, although patients did allude to it, again in social terms:

‘Well, I didn’t know what to expect at all and C/SN2 said you will enjoy it because there will be people there to talk to. I said well, she said, if you don’t enjoy it you don’t have to go back. Anyway the first week I went they were very very nice. I had to go and see the doctor there because obviously they want to know your history and there were these ladies there and we all got
chatting, and everyone calls everybody by their first name. And what you don’t mention is cancer. They never mention the word. We do different activities every week. For Valentines day we did glasses, we painted glasses.’ (C/P1)

 Whilst referrals to day hospice services for such social reasons appeared valid to referring health care professionals, referrals to other health care services for social reasons were felt to be ‘inappropriate’. This distinction appeared to be validated by those working within the hospices, accepting that providing social support and companionship to patients was a useful introduction to the hospice. Research supports this view, for whilst there are day hospice services which perceive themselves as offering a more ‘medical’ or ‘social’ approach, their role in providing social care is certainly accepted as providing valued support to patients and carers, and acting as an introduction to future hospice services (Spencer and Daniels, 1998; Higginson et al., 2000; Goodwin et al., 2002a).

 The acceptance of a social model of care within the day hospice as part of a ‘package’ of hospice services stands in clear contrast to the ‘inappropriate’ referrals for social reasons discussed by other respondents. This was particularly clear in discussions with district nursing respondents, with keenly felt distinctions between health and social care, and discussion about the difficulties they had in negotiating care with social care services:

 ‘Because there is that difference still between nursing need and social need, and getting washed is still not a nursing need, although her prognosis is less than three months, and this is the problem we have with Social Services, if you mention the word palliative to them they say no and won’t, but if there’s no actual nursing need then they still need social services to help them.’ (A/DN3)

 Nurses often felt that referrals to nursing services should be for clearly identified nursing needs, regularly defined as technical nursing tasks, rather than for fundamental caring needs such as help with hygiene requirements. However two issues with this were apparent. First, there were differences of opinion between nurses on whether such distinctions between social and nursing care should not be made in the case of palliative care. Palliative care could be seen as an exceptional case, where the normal referral protocols to social care services would be suspended in acknowledgement of the anticipated time limited period of care and the special nature of palliative care patients:
‘Usually if we get in a palliative care patient, they tend to be towards the end stages of the disease, and we take on their social care, you know hygiene care.’ (C/DN1)

Second, a key criterion appeared not to be the care task per se, but the prognosis of the patient, as it was widely accepted that the district nurse would either share or take over such care once the patient was in the terminal stages. Therefore an absolute definition of social or nursing needs was not being applied, rather one which took account of the caring context. Such a flexible definition could consequently be applied in different ways by different professionals, and could also be influenced by their interpretation of the gradations between terminal and palliative care:

‘If I know that it is going to be long winded, but that early on they are going to need help washing and dressing, I will get homecare [social care service] involved. Because, we don’t have the time, we don’t have the capacity to go in and get somebody up and washed and dressed every morning and what have you. Homecare do; that is their job. So we kind of job share and we work quite well with homecare as well, they know that if there is a problem they ring us direct and vice versa, and then it’s only in the latter stages where we work more closely, we might interact together on a visit or they go one hour and we go the next hour and stuff like that, so we swap all. They pull out altogether at the end.’ (B/DN3)

For the district nursing service in particular, providing palliative care meant that they could override the normal, albeit complex, distinctions between social and health care which they enacted in their everyday practice to provide the ‘social’ care which they did not provide to other patients. It is important to emphasise that by ‘social’ care they did not mean housekeeping duties, but the provision of intimate, personal care to patients to meet hygiene needs. In the past such work was core district nursing work, but successive policy changes have effected the transfer of such work to social care services. Nurses have struggled in the past with this re-definition work, arguing that such care is more than just washing, but facilitates skilled assessment and observation of patients. Redefining such nursing work as social care is also difficult as health can be socially defined and social needs often have a health component (Griffiths, 1998).
Nurses in this study appeared confident in passing over personal care to others on the grounds of time and workload, but varied in their interpretation of this policy with their palliative care patients in how soon they ‘took back’ patients to provide care. This special treatment of palliative care patients by district nurses has also been described by others (Griffiths, 1997; Goodman et al., 1998; Austin et al., 2000; Luker et al., 2000) and is explored further in chapter 7. Worthy of comment here, especially in the context of the discussion of the relationships people form with patients discussed in that chapter, is the apparent disregard by nurses of any relationship social care staff may have developed with patients over time. This is reflected in the statement at the end of the previous quote, which could equally imply that social care staff are ‘pushed out’:

‘They pull out altogether at the end’ (B/DN3)

Despite these examples of the provision of ‘social care’ within day hospices, and at the end of life, social reasons for referral were generally perceived by the health care professionals within the study as peripheral and unimportant reasons for referral to themselves, rather than core health business. This is reflected in the documentary analysis of case notes, referral proforma and criteria, and assessment proforma. Social care was only mentioned explicitly twice, both times within specialist palliative care nurses’ documentation:

**Narrative from the printed referral form for referrals to the Community Macmillan Nurse in Case Study A:**

**Reason(s) for referral.** Please state the main problems that have led to the request for SPC assessment. Include relevant information on physical symptoms (including mobility), carer’s needs, psycho-social/spiritual issues and difficult ethical needs as appropriate. (Followed by 16 lines of free-text space).

**Narrative from the printed referral pathway from hospital to community Macmillan nurses in Case Study C:**

**Reasons for referral?** Pain/symptom control, psychological care/social care and support for patient, psychological/social care and support for lay carer, advice and support for professional, help planning future specialist palliative care.
Social care was not mentioned explicitly in any other referral or assessment documentation, nor given as a reason for referral in any case notes reviewed. In both cases above social care appeared to be considered as part of psychological care for patients and carers, and referrals for psychological reasons are considered next.

6.2.2 Psychological reasons for referral to community palliative care services

Defining the psychological reasons for referral appeared difficult for referring health care professionals. Most health care professionals interviewed discussed broad concepts such as ‘support’, rather than discrete clearly defined needs in terms of diagnoses or defined problems. ‘Support’ and psychological care appeared to be synonymous to many professionals, shown by these examples from Case Study B:

‘The two classic reasons [for referral] are for either pain and symptom control issues or the, you know the psychological support issues.’ (B/SN1)

‘…looking at how they coped at home, where we go from here, emotional support.’ (B/AH1)

‘in that case I was referring because of medication issues and because of psychological support issues for the wife.’ (B/AH2)

It was recognised that such ‘support’ visits could be seen as unfocused and lacking value, although some respondents argued against this:

‘We call them a support visit, but I think that people can just sometimes see that as a chat, but it’s not. We go in with quite a structure to the visit, so it’s going through, repeating your nursing assessment, doing a summary of that, seeing where the last, going through the activities of daily living and what has changed since you last visited, any symptoms, any pain, mobility, etc., and that. And then just sort of an open discussion with them, how are they coping, they might be undergoing treatment they might not be, and it very much depends on where the patient is at, as to whether we will be discussing things further on sort of like place of death, things like that and some people will discuss that and other people won’t.’ (A/DN5)

However, as can be seen in this data extract, even such focused ‘support’ visits also highlighted physical symptoms and aspects of care, and discussed
psychological care in broad terms such as ‘discussion’ or ‘coping’, rather than an investigation or assessment of the experience of any psychological symptoms. Others recognised that even such a broad supportive role may be difficult for some staff to provide, particularly if they were focused on the provision of physical care:

‘The better district nurses take a rather broader view of things, and I would hope and encourage, and usually our district nurses who we work with would be, also take on a supportive and advisory role. Even if there isn’t any hands-on nursing, though I have come across circumstances where district nurses tend to withdraw if there isn’t sort of hands-on nursing needs.’ (B/GP3)

The concept of a ‘supportive’ role is one which is discussed in nursing literature. Davies and Oberle (1990) discuss the dimensions of the supportive role of the nurse in palliative care. In-depth work with an expert nurse revealed dimensions of valuing, connecting, empowering, doing for, finding meaning and preserving own integrity. Core to their discussion is recognition that the nurse as a professional cannot be separated from the nurse as a person. This recognition that personal and professional factors interweave in care provision is further discussed when the way professionals relate to patients and to each other is explored in chapters 7 and 8. District nurses in particular continue to emphasise this supportive work, with recent research identifying the importance they place on early supportive visits in relationship building (Griffiths et al., 2006). Griffiths et al. (2006) also recognise the tension between district nurses recognising the importance of support as a legitimate activity and potentially lacking the skills to explore emotional and psychological needs.

The reluctance of generalists, particularly district nurses, to address emotional and psychological concerns was also identified by the respondents in this study. There was recognition that generalists were hesitant to provide such care, or they actively referred to other providers, usually Macmillan nurses, to access their skills, knowledge and time:

‘But there are those [DNs] who are quite nervous about the emotional intensity of looking after people who are dying or addressing issues around quite sensitive and emotionally charged issues.’ (C/GP 2)

‘If I found that the patient had needed some sort of help in that I couldn’t with my basic knowledge of counselling I couldn’t resolve, because they
[Macmillan nurses] have got obviously deeper counselling skills than we have.’ (A/DN 1)

‘Psychological issues … and I think very intense situations like that, I ask for Macmillan psychologically to come up for the patient.’ (B/DN1)

‘I think they [Macmillan nurses] are very good on the family support. Patients are totally unrealistic and talking about you know going to Florida in six months, when clearly they are going to be nearly in a box, then I feel they are good on direct conversation and opening up conversation.’ (B/AH2)

‘And they [patients] often have fears and questions, which need, if not going over, addressing. And they [Macmillan nurses] will do that. And they will be intuitive in talking to the family and what they are to expect and so on.’ (C/GP3)

These referrals appeared to relate as much to the professionals’ skills and needs as to the patients’. The trigger for referrals appeared to be recognition of a skill deficit in the referring professional, rather than an assessed problem for the patient or their carers. These skill deficits were particularly noticeable when professionals were talking about emotional or psychological care, with very little discussion of particular situations which would trigger a referral to specialist palliative care. There may also be concerns about the referrers’ own emotional capacity to care, and research reveals a number of strategies such as emotional shielding, processing and postponing used by nurses to deal with such issues (Sandgren et al., 2006). It may be that onward referral to others also facilitates emotional survival.

Respondents were likely to use words such as ‘intense’ or ‘deep’ to discuss the circumstances triggering a specialist referral, and broad terms such as ‘support’, ‘getting their heads around’, ‘really struggling’, rather than explicit symptoms or issues such as anxiety or depression to describe patients’ problems. In particular, no examples were given of medical referrals, for example to general practitioners, when a psychological problem was detected. Where such terms as anxiety or depression were used in referrals, it appeared they were not always used in a way which the specialist felt was appropriate:

‘You know I have had referrals about people being sort of depressed and when you go in, I mean it’s difficult to know where sadness ends and where depression begins, but I wouldn’t say they would be actually depressed. They are trying to either come to terms with the situation or they are just very sort of like sad about the losses they are experiencing but they are very, if you like content with the district nursing that they are getting.’ (B/SN1)
One particular circumstance when referrals for psychological care to specialist services were discussed by a number of respondents related to the age of the patient. Typically, a younger patient, often where there were challenging family dynamics, would be more likely to be referred to specialist palliative care providers. Again, such referrals were as likely to be couched in terms of additional time available, as the expertise likely to be offered:

‘Psychological support, if it is somebody, a patient or one of the carers who was really, really struggling for whatever reason, maybe because particularly for the younger patients, the problems that the family are having just getting their heads around the diagnosis of cancer. Anybody that I feel psychologically would benefit from that extra support and again as district nurse I would be thinking about the time factor, that maybe a Macmillan Nurse going in that could set aside an hour and a half, maybe two hours to spend with that patient that would be beneficial that as a district nurse would be very difficult for me to do.’ (B/SN2)

Psychological care therefore appeared non-specific, with respondents lacking the language to adequately describe why they were making referrals. They expressed concerns about their ability both in terms of time and expertise to meet psychological needs, but recognised the importance of providing ‘support’ to patients and families, often to facilitate building an ongoing relationship.

This lack of clarity about psychological needs and ‘support’ was also reflected in their documentation of care. Indeed, the referral and assessment proforma collected rarely explicitly asked for information about the psychological status or needs of patients. Whilst psychological support was sometimes broadly mentioned within the referral criteria for some services, the opportunity to explicitly document this was infrequently given:

**Narrative from guidelines for referral to community specialist palliative care, Case study A:**

*‘Reason for direct patient contact by specialist palliative care team in conjunction with health care: Complex psychological and spiritual support.’*

In the referral guidelines above, no guidance on what constitutes complexity was given. In the generalist district nursing assessment documentation analysed
psychological care needs were rarely recorded or requested, which would possibly restrict the identification of issues where specialist input would be beneficial:

*Extracted from district nursing records, Case study C. Proforma asks for elements to be recorded under the following headings, each within a small boxed area to record minimal information:*

*Nursing assessment elements to be recorded: mobility, safe environment, breathing, nutrition, sleeping, elimination, communication (hearing and vision), personal care, state of mind, body image, interests, dying, risk assessments, baseline observations.*

*Extracted from district nursing records, Case study A. Proforma asks for elements to be recorded under the following headings, each within a small boxed area to record minimal information:*

*Nursing assessment elements to be recorded: safety, communication (hearing and vision), mobility, diet, fluids, elimination, skin, sleeping, breathing, allergies. Behaviour (memory, temperament, compliance).*

In the extracts above, there were only one or two elements which would relate to psychological needs, in comparison to the range of physical needs to be assessed. There was no evidence in interviews, observations or documentary evidence within any of the case study sites of formal psychological assessment of patients or carers being carried out.

There appeared to be a mismatch in the data between the feeling that supportive care which incorporated an emotional and psychological dimension was legitimately part of palliative care provision, and a difficulty in specifying exactly what the psychological and emotional needs of patients were and whether and how they could best be met. Certainly, the provision of psychological and emotional support appeared to be a significant trigger for referral particularly to specialist palliative care nursing services so they could support others in their role. Referrals for emotional and psychological care can comprise a large proportion of the reasons for referral to Macmillan nurses (Skilbeck *et al.*, 2002). However, the vagueness of such definitions of care and need may cause problems in referral, where the person referring and the person accepting the referral may not share the same frame of reference on emotional care and support leading to differing expectations about therapeutic outcomes as well as the nature of the workload (Skilbeck and Payne, 2003). A mismatch of referral expectation and outcome may
cause problems not just for the patient referred, but could affect the likelihood of referral in the future, and this is discussed further in chapter 8.

6.2.3  Physical reasons for referral to community palliative care services

Physical reasons for referral dominated discussions of why referrals to palliative care services were made. Referrals were highly likely where there were defined, ‘obvious’ physical needs – to ameliorate physical symptoms, to perform technical nursing tasks, or to monitor a response to treatment. Nurses in particular often described such referrals as ‘routine’, or ‘legitimate’, and conversely indicated they may be less likely to visit a patient where such needs were not identified:

‘I’m just trying to think really, um if they’ve got like constipation, things like that, that are, you know, just are routine nursing needs.’ (A/DN4)

‘Because the district nurse might go in and do an assessment visit and not need to go back. There are no actual nursing needs at that time.’ (C/SN1)

‘Sometimes it’s for erm…it sounds awful this…legitimate reason [laughs], like they’ve you know had major surgery or they’re receiving chemotherapy or radiotherapy, or they’ve been catheterised or they’ve got a urostomy, colostomy, da-de-da-de-da.’ (C/DN2)

The role of district nurses in particular in meeting physical needs and performing technical nursing tasks was also recognised by patients:

P: ‘Well I had a Hickman line in my chest, and I had chemo, so they had to come every Tuesday to flush the lines, to keep them patent, so they came every Tuesday, but I’ve had that taken out now, so I’ve got these stitches that can come out today…. But they are a real support, like they have been asking how I’m coping, have I had any trouble with my line, just basic things, but they are really nice. So like if you have any worries, if you are worried about your lines you can phone anytime at night, weekend, it doesn’t matter we will be out, so it’s just knowing that you have that support there if you need them.

I: So now your lines have come out, are the district nurses going to be continuing to visit you?

P: No, I don’t think they will …but unless I have a problem then I don’t think I will need to be in touch with them again.’ (B/P2)

Indeed, in this data extract, the patient’s expectation was that the district nurses would no longer visit, when the requirement for such ‘technical nursing’ had
passed. Nor did they perceive that they would need district nursing services. However, nurses often recognised that referral for such technical tasks allowed them to be involved early with patients, and facilitated them developing a relationship with those patients for the future. This was noted by district nurses in a study of their role in giving palliative chemotherapy, where they recognised that such technical care facilitated and legitimated the development of a future supportive role (Andrew and Whyte, 2004).

There was widespread congruence in the interviews and case note analyses of the relevance of such referrals to generalists, and to district nurses in particular. These were uncontroversial referrals, widely seen as evident and necessary to meet clear patient needs. Less clear cut were the triggers for referral to specialist palliative care services for physical reasons:

‘Well it’s fairly easy really because I know the Macmillan nurse is not going to do any hands on nursing, so if it is a nursing problem I would definitely, if I felt the patient should be considered for catheterisation, or had got a bowel management problem I would have no hesitation to ask for a district nurse and that wouldn’t be a problem at all. The decisions about Macmillan nurses are a bit more complex, it’s more to do with symptom control that I think.’ (B/AH2)

‘I think the Macmillan nurse will be more inclined in doing you know the pain management, and the district nurses, will also be doing the same, but I think they would be more generally also for the patient, if there is any dressing to be done, or anything along with that needed, you know, that will help that also. The district nurses, I think their roles overlap; it’s not clear cut, is it?’ (C/GP4)

There was recognition from generalists that the trigger points for referrals to specialist care were ambiguous, varying depending on the circumstances of the referral. The role overlap referred to by the general practitioner above was a critical statement, an issue not only because the roles were not well defined, but because the skills, knowledge and educational preparation of those filling the roles also varied. These issues are key to some of the concerns of roles and expertise discussed in chapter 7, and informs the discussion about relationships between general and specialist practitioners in chapter 8.

It was common for respondents to refer to patients who required referral to specialist services as ‘complex’. In this data extract below the issues of complexity
appeared to relate to not only the physical and psychological problems the patient was experiencing, but also to the complexities of having sufficient professional capability to address problems, and complex inter-professional relationships which required handling in a particular way:

‘I: So what would you regard as a complex patient? 
B/DN4: Probably somebody that’s not reacting well to treatment, that doesn’t, has very poor symptom control, pain relief, somebody who is very not anxious but is very up and down in the air with their emotions and stuff like that, somebody that probably could do with some counselling or something to go along with the diagnosis and stuff ... it just tends to be people that we don’t know what else to do for them. We have tried everything that we can do, GPs a lot of time we are knocking our head against a wall, whereas if a Macmillan Nurse goes in they get exactly what they want straight away. So I suppose it’s people who have a lot of problems, but people that we also can’t solve the problems for them.’

This is a potent statement illustrating what is developed as a central argument in the thesis: that patient’s needs and problems are only part of a complex rationale behind referral, and professional capacity and inter-professional issues play a large part in referral decision making. The use of specialists to influence the care of others as described here is explored later, but in this context is particularly relevant to referrals made to advise on and influence prescribing:

‘I always feel that the Macmillan nurses are very good on advice regarding medication.’ (B/AH2)

‘We would get the Macmillan nurse involved....you know, if it’s that type of pain why don’t you try this drug, get the GP to write that up for you and we will try that.’ (C/DN5)

‘Or we were not managing their pain as effectively as either I or the client would like, then I would ask them [Macmillan nurses] to visit and get, and to speak with the, me, in order to get more experience and maybe to try new things, because we don’t know everything that’s out there ... and there are new drugs coming out all the time which you know, Macmillan nurses tend to be get, get informed.’(C/DN2)

The exception to this appeared to be in Case study A, where there was little discussion of the use of specialist palliative care services to influence prescribing habits, possibly because of the problems accessing services described within that case. In the other cases these were examples of an honest acknowledgement of limits of competence in a particular field, thus using the available specialist
expertise to influence general practitioner’s prescribing. The two issues where
generalists, particularly district nurses, appeared to acknowledge that specialists
had beneficial skills to offer appeared to be this prescribing role and in the
provision of emotional and psychological support to patients.

In summary, professionals frequently framed making and receiving referrals with
reference to patients’ and carers’ physical, psychological and social needs. Whilst
referral criteria, assessment proforma and similar documentation focused on such
patient needs, discussion within the interview situation revealed that such needs
were rarely absolute. Whilst there were examples of ‘obvious’ needs such as
technical nursing tasks to be fulfilled by district nursing services, there were
indications that referral decisions for other needs focused not on an absolute
assessment of patient need, but on an appreciation of the competency and skill
base of both the referrer and those to whom the referral was made. These
influences on referral are further discussed in chapters 7 and 8. Other influences
on referrals are now presented.

6.3 Referral issues

Respondents explicitly discussed particular issues which they identified as directly
affecting both the referrals they made, and their likelihood of accepting referrals
made to them.

6.3.1 Appropriateness of referrals

A key concept to which respondents frequently referred was that of
‘appropriateness’. It was common for professionals to talk about appropriate and
inappropriate referrals, although rarely with an explicit definition of what was
deemed appropriate. Appropriateness appeared to be related to a perception of
the needs and desires of patients and carers, and the skills, interests and role of
the professional.

It was a common complaint that ‘inappropriate’ referrals were made because
others did not understand the role of the professional to whom they were referring.
For example, here, consultants were seen not to differentiate between the role of the Macmillan nurse and the district nurse:

‘They [Macmillan nurses] were inundated with referrals, and some of them were inappropriate for them, but they got all the referrals, and it still does happen as well, some of the hospital consultants, and even some of the palliative care consultants who say refer to the Macmillan nurse, and it isn’t the Macmillan nurse they need, it’s the district nurse, and so the Macmillan nurse does now pass them on to us and say, look I’ve had this and it isn’t appropriate, it’s a nursing assessment they need doing.’ (A/DN5)

Differences were also perceived between the role of palliative care specialists in the hospital and community settings. What may be perceived as an appropriate referral in the hospital setting may be seen differently in the community:

‘Particularly the hospital teams. They have a different perspective on things to the community. Because a patient has seen a specialist in there, they want to refer direct to us, without the district nurse. It may be that our district nurse copes admirably with that patient, but they feel that the patients have a right to our services because they have seen them in hospital, and it’s a whole different ball game out here.’ (C/SN1)

There was also a perception that blanket referrals of everyone with a particular diagnosis were inappropriate:

‘I think people partly don’t understand really what we do as specialist nurses, I think they just think that we are there to look after anybody and everybody that has got cancer or a life threatening disease or whatever. Sometimes new district nurses that come into post will refer everybody that has a cancer diagnosis to you.’ (C/SN1)

It was clear from these extracts that specialists believed that referrals should be made selectively – that it was inappropriate for every patient in the palliative phase of their illness to be referred to a specialist palliative care service. However what seemed to happen was that the role of the generalist in palliative care provision may not be recognised, and patients were universally referred for specialist care. The work of Clark et al. (2002) supports this finding, with hospital Macmillan nurses in their study commenting adversely on the policies of the community Macmillan nurses when they insist that district nurses are involved in every patient they refer.
However, this sense of appropriateness was difficult to explain to others – both because those making and receiving referrals recognised that appropriateness depended on the varying abilities and interests of the professionals making and receiving the referral, and that what appeared to be an inappropriate referral to the person receiving the referral can be appropriate when actually assessed:

’Soo it was appropriate for me to go, but not in the way it was initially requested.’ (C/SN2)

‘There’s a very specific block of patients that you would expect would be a referral, and then there’s some patients that they’re in a little bit of a grey area, and depending on the knowledge, skills and expertise of whoever is referring the patient in, if, if it’s not very good then you’d have more input, but if they were very skilled and very experienced, then you may have very little input, and it was more fluid.’ (A/SN4)

These extracts highlighted key difficulties in appraising appropriateness, that what was perceived as appropriate was not fixed, but flexible. First, specialists were driven by the referrals of others, and knew that these referrals varied in their perceived quality and comprehensiveness. Second, they also reported that their own specialist assessments revealed previously unknown issues. They cannot therefore always rely on the information within the referral to judge whether the referral was appropriate or not. Indeed, the documentary evidence of the referral forms used would indicate that there was rarely the space to record sufficient information about the patient to determine whether a referral would be appropriate from the form:

**Extract from field notes regarding generic referral form to hospice, case study B:**

‘The form appears to have been designed to be completed quickly by the referrer, with a “tick box” approach. It is two sides of A4. On the first side most of the information is demographic; address, date of birth etc. There is a section for details of illness, with half a line of A4 space given over for each of the following; primary and secondary diagnoses, and operations, chemotherapy and radiotherapy for treatment. It is therefore very focused on cancer treatment. On the second side there are two lines of A4 to record “reason for referral/main problems”, and then a space to circle the “requirements” the options being symptom control, respite care, continuing/terminal care, or rehabilitation. The care options can then be circled; day care, out-patient consultation, home care (nursing) or home medical assessment. The form requires a doctor’s signature.’
There was a real dilemma here as specialists knew that they depended on the accurate referrals of others so they were not overwhelmed with ‘inappropriate’ referrals, yet this risked problems not being identified by specialist assessment. This is a very real concern, as research with both specialist palliative care nurses and doctors reveals their awareness that their specialist assessments discover problems not initially identified by the requesting professional (Clark et al., 2002; Kuin et al., 2004). However, it is important to remember that problems are not necessarily synonymous with needs. Research has found that patients identified many problems which they experienced, but that they asked for more support for only a specific few (Osse et al., 2005). Certainly, in the research reported here, patients rarely complained about services received, or their appropriateness, even when it appeared that they had unmet needs:

'I: Would you have felt at that point that any of the services that you are now in contact with would have been helpful to you at that juncture in what was happening?

B/P5: It's hard to say really, I think it was me actually not reporting the diarrhoea, I just assumed that it was part of the condition and I really felt terrible throughout that period, ill, but it wasn't clear that it wasn't connected with the cancer and so on really. If I had reported the diarrhoea as a cause for concern earlier I think it may well have been dealt with earlier. I did see the district nurse prior to that being dealt with, but I don't know really, it might have been useful to speak to someone, I'm not exactly sure whether the district nurse, Macmillan nurse possibly … It's possible but I'm not certain that I would have mentioned it, perhaps to a district nurse if I had an earlier referral.'

The data from the patients indicated that they were generally reluctant to question the care they received, and were unsure about the most ‘appropriate’ person to turn to if they did experience problems.

Furthermore the appropriateness of the referral was considered to depend on the skill level of the referrer, hence a referral could be judged as more appropriate if it came from someone the specialist knew to have fewer palliative care skills or interests. Again, an issue of a ‘competence gap’ or even an ‘interest gap’ was raised by respondents as a key driver of referrals, which made a notion of ‘equitable’ service provision difficult to judge.
In addition to the variability in referrals deemed appropriate triggered by differential skills and interests in palliative care, teams were also reported to refer inappropriately because of a lack of understanding of the service offered:

‘Some district nursing teams may not recognise the role they could play in this for whatever reason, for all the reasons I’ve given, time constraints etc whatever reason that is, that oh well we will refer them to Macmillan because they can do that … when you get back to that person and you say why have you referred they say oh they have got cancer, they are dying there is no treatment for them, so that is what you do isn’t it.’ (B/SN2)

Such blanket referrals may be easier to understand when the attitudes of generalists to referrals into their own services are considered. It was common for district nurses in particular to feel that every referral to their service of a patient with cancer (rather than any other condition requiring palliative care) was appropriate:

‘Um, well, with the cancer patients I don’t think they [GPs] ever refer when they shouldn’t … because of the underlying condition I think, so if the GP’s concerned, we’ll go out, but we wouldn’t really question it.’ (A/DN4)

‘I: Do you ever get inappropriate referrals for palliative care patients? B/DN4: No. Not really. Because even if they are just asking us to go out and see them, we see that as part of our role with palliative care patients. So we do.’ (B/DN4)

There was a tension here in referrals with generalists like district nurses generally advocating universal referral of palliative care patients to them where possible, but specialists promoting selective referral of ‘appropriate’ patients. The desire by district nurses for all cancer patients to be referred to them has also been found by others (Pateman et al., 2003). Where this is fully understood and supported by generalists and specialists such a division may work well, however, if there are differential understandings of what is meant by ‘appropriate’ or concerns about the competence of particular practitioners then such divisions may mean that patients are not receiving optimal care.

Related by respondents to the issue of inappropriate referrals was the way that they controlled access to their services, sometimes to screen for ‘inappropriate’ referrals sometimes for other reasons. This is now considered separately.
6.3.2 Controlling access to services

Few of the teams within the case study sites studied had or used formal referral criteria to guide and control referrals into their services. Such criteria were generally found relating to referrals to specialist palliative care providers, and were often broad in their guidance:

**Narrative from ‘Criteria for direct patient contact by specialist palliative care team, community Macmillan nurses, case study A:’**

‘Pain control: uncontrolled or escalating pain.
Symptom control: incomplete symptom control, side effects, complex multiple problems.
Psychological support: complex support
Patient dying: to achieve symptom control and psychological support
Communication: difficult issues i.e. collusion, denial.’

**Narrative from hospice entry in palliative care directory, case study B:**

‘Referral made for any patient with problems arising from progressive illness, particularly malignant disease. Referrals accepted from GP or hospital consultant.’

Whilst criteria did exist for some services, there was scant evidence either that the teams themselves used them to determine the outcome of referrals, or that those referring into the teams were aware of or used such criteria. Indeed, there could be negativity about referral criteria, and how they could be used to control access to services:

‘Our community Macmillan team have been in a bit of disarray, the referrals into them were difficult to make because they wouldn’t pick them up basically, you had to fit the criteria for them to intervene, but when they did intervene it was very much a visit, a fax scribbled and that was it, they disappeared off the planet.’ (A/SN1)

Again, there were real issues about selective acceptance of patients, here related to referral criterion which the respondent appeared not to believe appropriate. The ineffectual nature of the referral criteria which did exist in the case study sites is in contrast to the firm belief that referral criteria would control inappropriate referrals found particularly in nursing literature. It is suggested that referral criteria for district nursing would restore control over district nursing workloads and control inappropriate referrals (Vafeas, 2000; Royal College of Nursing, 2003), and that
‘levels of intervention’ for specialist palliative care nurses would ensure their skills are appropriately used (Webber, 1997). This guidance issued by Macmillan Cancer Relief clearly influenced the work of the Macmillan nurses in the case study sites, with the ‘levels of intervention’ discussed in interviews and collected as documentary evidence in Case study C. The gatekeeping activities of district nurses are also supported by the influential ‘First Assessment’ document (Audit Commission, 1999), which recommended that district nurses should have responsibility for first assessment, whilst clinical nurse specialists focus on patients with more complex needs.

Rather than the use of referral criteria, it was more common for access to specialist services to be controlled by generalists’ informal gatekeeping activities, and such gatekeeping could be actively encouraged by specialist staff:

‘But sometimes when we get referrals, you know, we would actually get the district nurses to go in first and see whether specialist input is needed.’ (B/SN1)

[referring to hospice referral requiring a GP approval] ‘somebody medical… it sounds a bit precious, the medical profession being precious, but it does mean that it keeps an order, and avoids chaos … that somebody’s actually thought about whether it’s an appropriate referral.’ (B/SD1)

‘And we’re like little gatekeepers in a way, but I think it’s up to me to objectively tell them [the patient] what a Macmillan service does.’ (B/DN1)

‘Our Macmillan nurses like us to get involved first… let the district nurse make her assessment first, and speak to the patient, and if the patient says well I want to see the Macmillan nurse then I can refer over to her… but it tends to be the district nurse first and then the Macmillan nurse usually.’ (C/DN5)

Such referral etiquettes were also observed in referral meetings. In this data extract, referrals to the hospice and specialist palliative care services in case study B were being discussed, no district nurse was present.

**Notes from observation of hospice referral meeting. Case study B**

‘The discussion then moved to an in-patient who will be discharged home tomorrow. The background and medical history of the patient was discussed in some detail amongst the in-patient nurse, consultant and other medical staff who were present. A referral was made to the community Macmillan nurse (present at the meeting) and to the Hospice at Home nurse (who was not present as she was out seeing patients at the time). However, it was then
made clear to me that the community Macmillan nurse would not visit or assess the patient, despite the knowledge of the patient she had gained at the meeting, but would wait for feedback from the hospice at home nurse and district nurse before any referral would be activated. If they didn’t think it necessary, then she would not visit. I was left wondering what the point of the discussion had been, and to whom it had been relevant. The community Macmillan nurse now knew a lot of detail about this patient, but did not appear to make any plans to share this with the district nurse.’

These informal gatekeeping activities had developed in the case study sites into what appeared to be negotiated etiquettes of care. These etiquettes appeared to achieve several objectives: they controlled the specialist’s workload by ensuring that patients were screened before referral, they prepared the ground with patients before referral and they re-affirmed the importance of the generalist provider to the specialist. As discussed in section 8.3.2, developing a relationship between generalist and specialist was seen as critical to care. These generally unwritten protocols appeared to facilitate relationship building because the specialist was able to hand some elements of control and power to the generalist in return for a more regulated caseload. This was not without its risks, as its smooth operation depended on the actions of the generalist, some of whom were less likely to make what the specialist deemed to be appropriate referrals, or to fully understand the role of specialists.

Methods of controlling access to community services are recognised as essential where levels of workload are not arbitrarily defined by bed numbers or other control mechanisms. Whilst policy documents have focused on criteria and guidelines, research in other fields reveals other ways of controlling access to a finite resource mediated by the professionals involved. Research with community mental health teams reveals tactics of ‘buffering’ (delaying tactics) and ‘gatekeeping’ (ways of refusing referral) (Griffiths, 2001). The negotiated etiquettes discussed between general and specialist nurses may act to both buffer and gate keep referrals in similar ways.

6.3.3 Reluctant referrers

A recurrent theme in the discussions of referrals within the interview data was that of reluctant referrers – either the respondent’s own reluctance, or their experience of others’ reluctance. This appeared to focus around three main issues: their own
expertise in palliative care; their prior experience of referrals; and protection of the patient.

The respondents’ perceptions of themselves as having a certain degree of expertise in palliative care could lead to reluctance to refer on to others:

‘Never needed to refer to the community Macmillan nurses for psychological support because I’m trained, so that’s not a need.’ (A/SN1)

‘I don’t refer patients directly to the Macmillan nurses; I don’t know what they can offer that I can’t.’ (B/GP1)

Respondents with these views had a perception that specialist palliative care had little to offer that they could not. In a sense, they felt they acted as specialists because of their experience and expertise. This was usually related to home based advisory services like the community Macmillan nurses, rather than medical specialists or hospice care. Others’ research corroborates these findings. In section 2.3.5.1 research is discussed that indicates that generalists may be reluctant to refer to specialists if they feel they can provide good care themselves (i.e. Fellowes et al., 2003; Todd et al., 2002; Hanson et al., 2005).

Sometimes this was perceived poorly by others, who did not share the individual’s view of their own expertise:

‘I think there are people out there who don’t know their limitations, and will say “I don’t need to refer through to Macmillan nurses because I can do it”.’ (A/SN3)

Such reluctance could also be related to an attempt to protect the patient from the harsh reality of death and dying by making a referral to a service which may remind people of their illness. This was particularly seen with reference to referrals to specialist nurses, where there was a distinct perception that patients may perceive the referral in a negative way:

‘They felt we would be talking about death and dying, and be doom and gloom, and so they are very much put off seeing us until they get more poorly.’ (B/SN1)

‘You wouldn’t use the word Macmillan nurse until you had done that groundwork really.’ (C/GP5)
Patients' perceptions of referrals is explored further in section 6.3.6, but their actual perceptions could be less important to referral decisions than the way professionals thought they may perceive a referral to specialist palliative care. Much of the literature in section 2.3.5.3 supports this, with studies reviewed indicating that professionals defer or decline referral if they feel that patients are unwilling (i.e. Aitken, 2006; Friedman et al., 2002; McKenna et al., 1999). Research into general practitioners referral patterns to hospital services demonstrates large variability in referral practices between practices and individuals (Fertig et al., 1993; Jorgensen and Olesen, 2001; Hull et al., 2002), with perceptions of patient preferences a potential influencing factor (O'Donnell, 2000). Professionals’ perceptions of what patients want may therefore be a potent influence on referral practices.

These three factors could combine or work independently to act as potent barriers to referral, irrespective of the assessed needs of the patient for care.

**6.3.4 Timing of referrals**

It was widely accepted across all the cases that early referrals were better. Whilst referrals to specialists were sometimes delayed, often for reasons of patient protection and referral etiquette, generalists in particular valued early referral. As discussed in section 7.3.1 building a relationship with a patient was perceived to be core to good care, and facilitated by knowing people over a long period of time. The association between early referral and relationship building is noted in other research with district nurses, where a clear preference for early referral was found (Austin et al., 2000; Luker et al., 2000; McHugh et al., 2003).

The protocols used within the cases to facilitate early referral varied. In case study C there were no formal procedures to facilitate early referral, so staff relied on working closely with those who referred to them to facilitate timely referrals and to prevent referrals precipitated by a ‘crisis’:

“Well if you can’t get through to the GP that you need to be involved well in advance and not just when they need the nursing care, then you are never going to be able to do that good palliative care, because you’re always going
to be crisis managing. So you have to be able to get through to the GP when you need these patients referred to you.’ (C/KI3)

General practitioners reported that they were generally aware that others wanted early referrals:

‘If it’s very clear that this patient is going to be needing a lot of care over the coming days, months, or sometimes years, so that they develop a relationship [I refer to district nurses], and I think that’s really important.’ (C/GP6)

However there were still reports of referrals being made at a stage later than would be liked:

‘I’m afraid we don’t get involved sometimes that early, and I feel that’s a downfall because we need to know the patient much sooner before you know the disease gets progressive … unfortunately there is a high percentage of people referred to me in an advanced stage.’ (C/DN5)

In case study B there were protocols in place to facilitate referrals from hospital to district nurse, as a system had been put in place to fax district nurses directly from the hospital at time of diagnosis for oncology patients. This was not a visit request, but a transfer of clinical information. There was no similar protocol for any palliative care patients who did not have a malignant disease. However, the impact of this system appeared to depend on the view of the individual receiving the information. Some responded by contacting the patients to introduce their services:

‘Yes, we made that agreement between ourselves, the hospital and Macmillan nurses, that any patient in our area that is diagnosed with cancer or any terminal illness, then we want to be made aware of it, because it may not affect us now, we may not need to do anything. But I know at some point I am going to have to, and so I like to build up that relationship, that bond up before that point comes. Even if we just ring and visit once a month or whatever.’ (B/DN4)

Others did not respond immediately to this information because of caseload pressures, commenting that if the patient were referred later, then this initial information was out of date:

‘I can see why they did it, and to keep you informed, but then we’ve got such a load of patients on the books then we, we’re creating a file of information on people we’re not, we’re not acting on. Because if they, if we do need to see them later on that information is changed.’ (B/DN2)
Specialists also commented that this system did not necessarily work:

“There is on paper an expectation that all patients should be referred to the district nurses….they should be known to the district nurses, but it’s not infrequent for us to be asked to admit somebody who is not known to the district nurses, or hospice at home being asked to be involved with somebody’s care, district nurses only visiting once a month, once a fortnight, so that the reality is very different to the intention of what they would say they want to do … and I think the nub of that is that they’re an incredibly stretched service.’ (B/SD1)

The protocol therefore seemed less important than individual variation in response to and use of this information in making clinical decisions about accepting referrals and providing care.

In case study A, protocols existed in most of the practices because of their adoption some years previously of the Gold Standards Framework (GSF) (Thomas, 2002). Where practices were using the GSF then they generally had mechanisms (often regular meetings) to discuss patients with the wider primary health care team, to ensure that people were aware of patients, and that they were referred at an ‘appropriate’ time. As in case study B, the impact of the framework again depended on the views of the individual professionals to the referral and their role with that patient:

“But now under the Gold Standards Framework we get involved much earlier on, so when a patient is confirmed as having a palliative care diagnosis we get informed … so we make contact with the patient and then we go out to do an assessment.’ (A/DN5)

“So we get to know about patients, um, at diagnosis really, and we haven’t got the staff at the moment to be able to follow them all up.’ (A/DN4)

“I’d like to say at the time of diagnosis, um, but generally, sometimes it’s crisis … I think the Gold Standards Framework, everybody should actually be involved at the same time, but whether that works in practice, I’m not so sure.’ (A/SN2)

Perversely, the protocols and meetings which meant that staff were always aware of patients, could have a negative impact on visiting patterns. In case study C, without protocols, staff had to work hard to facilitate patient referrals, and tended to maintain some contact where possible to ensure they were aware of what was happening with that patient. In case study A, because they were party to regular
discussions about the patient and their progress, some staff did not necessarily feel that they had to visit, but could wait until the patients had explicit ‘nursing needs’:

‘The ones who are on the active list, we look at how things may well progress, we tell the patients what we’re doing, they know we talk about them, get their permission, and then I will have contact with them ideally. I don’t always, but they know who I am, they’re given my contact number, and as soon as they start to deteriorate I ask them [patient] to let me know.’ (A/DN3)

This also affected discharge behaviour – with more discussion of active discharge behaviour in case study A, in contrast with case study C where a discharge from a district nursing case load of a palliative care patient was rare:

‘Once that nursing need was treated they would just know where we were, because, you know, we’d just say if you’ve any problems just ring the district nurses at the surgery, I mean we do discharge patients, but it’s so easy to get re-referred, all they [patients] have to do is ring up.’ (A/DN4)

‘I would keep them [palliative care patients] all… I mean they would have to be going out of the area or in somewhere for us not to be involved any more.’ (C/DN1)

This finding challenges an evaluation of the GSF, which indicated that such protocols prevented patients ‘falling through the net’ (King et al., 2005). Whilst patients may not ‘fall through the net’ because people were unaware of their existence, it may not necessarily be the case that they are receiving care from some practitioners any earlier. Because professionals did not have to work to ‘know’ patients early, and potentially were constrained by the workload pressures associated with continued early supportive visits, they may actually visit later. In addition, an onus on patients to contact staff when their needs change may create later referrals, as patients can be reluctant to take the initiative in making decisions about care (Beaver et al., 1999a).

Generally respondents were positive about early referrals to facilitate relationship building with patients. However, for some, the reality of the response to such referrals could be very different – either because they failed to see the value of early involvement with patients, or they did not have the resources to offer such care. Again, access was impacted not necessarily by protocols and procedures which should facilitate equitable access based on need, but on an individual
professional’s interpretation of patient need relative to the resources they currently had available within their workload or caseload.

6.3.5 Patients’ characteristics

A major issue which emerged from the literature review in chapter 2 was the possible influence of patient characteristics such as age, gender, ethnicity, marital status, and disease status on utilisation of palliative care services. These were not issues which arose strongly from the data in this study.

Patient characteristics which were mentioned to some degree were age, ethnicity and presence of carers. Younger patients were felt to be more difficult to care for, because of the emotional difficulties for patient, carers and staff of caring for someone whose death was perceived to be untimely:

‘We’ve had situations in the past where, in particularly difficult cases, like a young woman and four young kids was one instance … I would have found it very difficult to look after the young women with 4 kids, emotionally that would have mashed me up.’ (A/GP3)

These emotional difficulties and the different effects diseases were perceived to have on younger people, meant that sometimes care was given in a different way to that described for those who were older:

‘Similarly a recent brain tumour that we had that was a GP referral, well brain secondaries and because he was rapidly becoming very poorly, a young man we went straight to the consultant and said, although you don’t know this patient, will you see him urgently and they moved really quickly to get him sorted and get some radiotherapy.’ (B/AH2)

‘She actually went to, because she had young children, very young children, and her husband was finding it difficult, she used to go into the hospice during the week and come home at the weekends.’ (C/DN4)

Respondents described these differences not as discrimination, but as an honest response to a situation which was assessed as being difficult to manage. In a similar fashion, they argued that their response to those from black and ethnic minority communities was equitable, where they responded to the assessed needs and preferences of those who were referred to them. For patients referred from Asian families, there was often a description of a different pattern of care because
of the perception of better family involvement in care, and a dislike of palliative care services:

‘Their families feel they have to support them, they can’t just leave them in the hospital to die and things like that.’ (C/GP4)

The data about caring for those from black and ethnic minority populations were particularly found in case study B, which had a higher Asian population than the other two case study sites:

‘More Westernised, there used to be a feeling, oh well, families would look after their own, but I think that’s not always the case, but I think there is a scepticism about the hospice and what they provide and can they meet our needs from the cultural and religious perspectives.’ (B/SN1)

The influence of general practitioners from the same cultural background as patients on referral patterns was also discussed by this respondent:

‘If their GP is from a black ethnic minority group, and I know sometimes that’s fostered by those groups, I know sometimes there are some of those GPs who don’t regularly refer as perhaps the white GPs.’ (B/SN1)

Hospice services could also be perceived as not sensitive to the needs of these patients:

‘We have done training on ethnic awareness and things … maybe thinking the hospice is perceived as Christian as opposed to being neutral. I don’t know, maybe it’s to do with fatalism in their perception of illness … the end result is that they don’t come here [the hospice] very much and despite all this effort haven’t done so.’ (B/AH2)

There was a strong sense that when patients from black and ethnic minority groups were referred to services there was no active discrimination or sense of inequitable treatment:

‘It doesn’t matter to me, their ethnicity; they get the same service as everybody else.’ (B/DN1)

But again, a feeling that such services were taken up in a different way because of the different influences within the family situation:
‘It’s not saying that we don’t offer the services and the facilities, but they tend not to take them up, because they do really use their family members … If their needs are no different from a white person’s, say I had two referrals, they are treated no different or whatever.’ (B/DN4)

The importance of family and informal carers also came through generally, not just in the care of black and ethnic minority patients. Family and informal carers were seen as important in affecting the response of patients to referrals and care:

‘I think they [family] think they can do it on their own and they don’t like people interfering, that’s really why, why, what I see they don’t like interfering, they like to do it themselves and sometimes they don’t cope well, a lot of the time they don’t cope, they won’t say no ‘cos they’re always aware that they don’t have to go into hospices or hospitals ‘cos that’s one thing a lot of the patients say “I don’t want to go into hospital to die” and they are aware that but some families want them to go into hospital to die so it’s a bit tricky.’ (C/DN3)

Professionals also acknowledged that the presence of family and informal carers could be essential to the care of patients at home, and would affect how they referred patients on to other services:

‘I am quite happy to look after people at home if that is their wish, obviously if there isn’t family support then that is a different matter because inevitably however much services and support you have from Macmillan nurses, district nurses and yourself going in, you’re not there 24 hours and so sometimes there isn’t that choice even though people’s preference might be to stay at home. If they don’t have a good family around them it’s difficult.’ (C/GP5)

‘Well if somebody is end stage and they are very very poorly and relatives are finding it difficult to cope and getting exhausted, we would suggest that [referral to hospice at home].’ (A/DN5)

What appeared to come through clearly from all of this data was not a sense of active discrimination on the basis of particular patients’ characteristics, but a sense of responding to needs and concerns in an individual way.

The importance of patient-centredness to health care professionals is found in other research. General practitioners make treatment decisions on the basis of such patient-centred issues in preference to evidenced based guidance (Armstrong, 2002). Gerrish (2000) also found that district nurses have a strong conception of individualised care which accommodates the needs of different
patients. She relates this to their concept of equity – they saw that this individualised approach to care meant that all patients were treated the same. This is re-emphasised in later work where community nurses equated professional care with liberal equality, where they assumed professional attributes of fairness and equity through being able to provide holistic, sensitive and reciprocal care. Such equality of care is seen as intrinsic to their everyday work with patients, seeing themselves as impartial, fair and just, despite the practical demands and resource constraints in their day to day work (Aranda, 2005).

It appeared that patients’ characteristics were important to professionals as one influence affecting their approach to care and referral, however they did not openly report any systematic bias in how they responded to such referrals. It may be that disparities in access were truly related to disparities in clinical need or patient and carer preference, and hence clinical response, that there was some as yet unknown factor affecting apparent inequity of access, or that there were discriminatory influences not revealed by this study.

6.3.6 Patient choice: the perspective of professionals and patients

Patient choice is emphasised in much UK palliative care policy, and giving patients information to make informed choices about their care is seen as essential (NICE, 2004). Health care professionals in this study talked about patient choice, and saw it as very important, operationalising choice as asking patients about their preferences regarding referrals, both to other services, and regarding their own service:

“We might deem in our assessment that they’re not ready for Macmillan, but then you don’t, we don’t know what they’re feeling and they might need or want to speak to a Macmillan Nurse, so I always give everybody the opportunity and the offer of seeing a Macmillan Nurse.’ (C/DN2)

“So we do the initial nursing assessment and take it from there basically and then we let the patient decide what they want. So some patients will say yes they want us to go back, others will want us to ring them, others want no contact and they will contact us. Sometimes they say oh well you decide, but we always put the ball back in their court and say “no it’s your decision, what do you want?”.’ (A/DN3)
Generalists reported offering access to care irrespective of their own assessment of what may be required. Whilst superficially such a response to patient requests appears admirable, there are two issues. First, if a referral to a specialist was at the patient’s request rather than the generalist’s assessment, the specialist may feel that the referral was inappropriate then they may not visit, or only visit once. This may mean that patients’ expectations of care had been raised and then not met. Second, patients were unlikely to fully understand the role of different services, and may therefore either wrongly accept or decline the offer depending on their assumptions about the role. Such choices appeared not to be informed choices, with patients aware of the way services work and their options. Patients and professionals were aware of these dilemmas:

‘I don’t really think patients understand what people’s roles are really, particularly with Marie Curie and Macmillan and, you know the district nurses and things, … so there is a misunderstanding of what the roles are and what people do.’ (A/SN1)

‘You see I wouldn’t know what, the only other thing is I wouldn’t know what services were available, you know what I mean, I’ve just accepted the services that have been offered … I don’t know whether I had any expectations really, I just didn’t have any information about district nurses at that time.’ (B/P5)

‘I: Is that what you expected the district nurses to do?  
C/P2: Not really.  
I: What did you think the district nursing service would do for you before they actually arrived?  
C/P2: Well, quite honestly, I didn’t think.’

Patients also reported that they discussed with particular professionals only those issues which they thought were appropriate, so that mis-apprehensions about role did not just affect referral, but ongoing care as well. In this example a patient did not discuss any concerns relating to her cancer diagnosis with the district nurses when they attended to remove stitches following a cancer-related operation.

‘No, they didn’t talk about cancer issues. Mind you, I didn’t talk to them about cancer issues. I didn’t bring it up because I thought she is here to attend to the scar.’ (C/P1)

Whilst it may be that patients would not know about services before a particular illness or need arose, the work of others indicates that patients who may be in need also do not know about services. Research with patients with motor neurone
disease has found that they do not know about services, about service entitlements or who to ask regarding services (Hughes et al., 2005). A small study of patients’ views about specialist palliative care nurses also found that although they valued the nurses, they did not fully understand the role of these nurses (McLoughlin, 2002). Awareness and knowing about services is also discussed in section 2.3.6, where research indicates lack of knowledge of services, and lack of understanding about what services offer.

However, it appeared in this study that what was important to patients and professionals was not just that patients knew enough about services to allow them to make an informed choice, but their views about services. The stigma and fear surrounding palliative care concerned professionals and patients, causing services to be declined or deferred inappropriately:

‘I think it’s that sort of like Macmillan title, that sort of like if you are seeing a Macmillan nurse the perception is you know, you must be in a bad way, you know, and so I think there is still a lot of that, the concept of hospice, although it’s not just a place for dying, we all know that but generally speaking there is still a misconception out there that that’s the case.’ (B/SN1)

‘In fact when me GP said it, would you like me to refer you to the Macmillan nurse, I was shocked. I was just shocked.’ (B/P4)

Choice in service use was not just an issue at referral, patients also reported that the choices that professionals gave them in visit frequency were difficult, as they were concerned about ‘bothering’ professionals. A strategy intended to empower patients therefore appeared to restrict access:

‘I think it’s that I, I don’t feel like then that I’m sort of mithering them [to phone when I need them], you know, I need that appointment. They’ve given me that appointment, they’re happy with that, I’m happy with that. Okay if there is anything in between they know that I’ll only ring if it really is desperate.’ (B/P1)

Patients also reported making choices on the basis of convenience and speed of response, not necessarily the expertise or role of the professional. For example this patient discussing how they would choose whom to see if they were in pain:

‘If I was at [out of area hospice] or going I wouldn’t bother making an appointment with them unless it was really bad, you know if it was a couple of days that I thought I might be in pain for then I would make an appointment at the doctors [GPs], but if it was something, I would wait until I went to [out of area hospice], just to save going to the doctors because you
can sit in the doctors for ages can’t you … I have to sit and wait and it’s alright doing that, but I can just go to [out of area hospice], go and see the doctor there and then she will fax a prescription through and then I can collect it.’ (C/P4)

Offering patients choices without adequate information to support this choice may therefore reduce access to services, particularly when patients may find it difficult to initiate contact with services. The reluctance of some patients to be active in their relationships with professionals is apparent in the work of others, discussed in section 2.3.6 where studies found patients are reluctant to ask for help, and preferred services to initiate contact (Seymour et al., 2003; Exley et al., 2005). A recent study of clinical conversations in palliative care reveals that patients often adopt passive roles and tend not to engage in some important decision making (Clover et al., 2004). Work with COPD patients also found they are reluctant to express needs even when prompted (Jones et al., 2004). Choice is also difficult with patients who are using denial as a coping strategy (Zimmerman and Rodin, 2004). It is also apparent that choice is offered in a different way by different professionals, leading again to patients’ differential involvement in decision making (Millard et al., 2006). Whilst patient choice is important in palliative care, it is also important to remember that choices must be informed by appropriate knowledge of services and patients’ likely roles in decision making. Otherwise it may be that a strategy intended to empower patients may otherwise restrict access to services.

6.4 Summary

This chapter considers the impact of several issues on how and why patients access community palliative care services: the interpretation of reasons given for referral; the consideration of whether referrals are appropriate; how access to services was controlled by professionals; the reluctance of some professionals to refer; the timing of referral; and how perceptions of choice can affect referrals.

The accepted terminology of referrals emerging from all the data sources was the ‘reason for referral’, inevitably couched in bio-psycho-social terms, and apparently used as shorthand in referrals to explain why a referral was being made. However these reasons appeared very constrained, often expressed simply as ‘for pain control’, or ‘for support’, and rarely explained in detail. However, there appeared to
be a complex professional rationale for referral, which was not necessarily encapsulated within the formal ‘reason for referral’. Such reasoning started to emerge when professionals explained when referrals were appropriate. They discussed the impact of their own and others skills and interests, and recognised that some professionals were reluctant referrers.

Clearly emerging was a sense of individualism, that whilst professionals took account of many complex issues when making referrals, there was no absolute assessment or definition of need which automatically would trigger a referral to a specific service. Rather there was a complex interplay of factors which mainly related to the individual professional and their decisions: their interpretation of the caring task and how it fitted with their role; their interpretation of the context of care with particular reference to their case or workload; their personal skills, interests and knowledge; and their perception of whether the needs could be met by others. The professional cannot be separated from the person, with all the complexity that people bring as human individuals to their roles.

Chapter 7 now addresses these issues in more depth, exploring how the professionals’ interpretation of their own roles in the provision of palliative care services affected how and why patients were referred.
Chapter seven

Professionals' perceptions of their own roles in palliative care
7.1 Introduction

In the previous two chapters the context of the cases and the impact of referral practices are explored. The data about the impact of the professional’s own perceptions of their role in providing palliative care on referral behaviour is now presented and discussed. Five main issues appeared to affect professionals’ constructions of themselves as palliative care practitioners and in turn their palliative care referral practices. These issues were: a sense of autonomy and self-management; patient ownership; expertise in palliative care; workload; and the impact of the perceived status of palliative care work.

7.2 Autonomy and self-management

Autonomy can be simply defined as ‘the right of a group of people to govern itself, or to organise its own activities’ (www.dictionary.co.uk), but used in complex different ways within other fields (Wade, 1999; Keenan, 1999). Autonomy is generally held to imply a sense of self-determination, where desired outcomes are selected and choices made about how to achieve them (Deci and Ryan, 1987). Autonomy appears to be a concept keenly debated in nursing in the 1990s, with several analyses published (Wilkinson, 1997; Ballou, 1998; Wade, 1999; Keenan, 1999). Keenan (1999), completes a concept analysis of autonomy with this definition: ‘Autonomy: the exercise of considered, independent judgement to effect a desirable outcome’ (p.561).

In this study, respondents rarely referred explicitly to autonomous practice – the term was only used twice in interview data, both times by specialist nurses referring to the way they exercised their roles. However, there were frequent discussions and descriptions of actions and judgements which appeared to be the ‘exercise of considered, independent judgement to effect a desirable outcome’ and a sense of a professional role in providing palliative care which implied a belief in self – determination. The professionals who appeared most likely employ such descriptions were the specialist palliative care nurses:

‘I can basically do what I like with my time, so long as I meet my target that I have set myself, you know.’ (C/SN1)
'We get on with the job and we realise that nothing is going to change, so we do our own management, we just self-manage … lets just get on and do it.' (A/SN2)

In this second extract self-management and self-determination appeared to be reluctantly integrated into the role, in this context in case study A because of a perceived failure of management to provide the organisation and direction expected of them, as discussed in chapter 5. Self-determination was also demonstrated by some of the specialist allied health professionals interviewed:

‘It’s just one of those roles that it can be partly what you make of it depending on how much you want to put in … it’s quite interested and varied … it’s knowing in your own mind quite what is right.’ (B/AH1)

Conversely, where self-determination was more constrained, specialist nurses could dislike this. An example is a specialist nurse in case study B, experienced in different care settings, who found working at the hospice more difficult:

‘It makes a difference [being based at the hospice] in terms of perhaps having less of an identity as a clinical nurse specialist from the point of view, I think a lot of people like see us as a continuation of the hospice.’ (B/SN1)

This nurse then went on to explain that they felt their role could be by-passed by working in this multidisciplinary environment:

‘Where there are consultants in palliative care, the specialist [nurse] role, although while it’s still recognised, it has the potential to be bypassed in terms of the GPs wanting to speak directly with the consultants, … and so perhaps your clinical nurse specialist is not to be utilised to their full potential really.’ (B/SN1)

In this situation, the specialist nurse did not feel they had a unique or central role in providing specialist information and advice, and compared this negatively to prior experiences, not in terms of patient outcomes, but in relation to the recognition and use of their own knowledge and skills in determining such outcomes. In this instance, a sense of autonomy appeared compromised by the perceived authority of others.

In contrast, it was rare for any doctors – either general practitioners or specialists – to make explicit reference to issues related to autonomy. The exceptions were
again where their sense of selves as independent, decision making practitioners was threatened – in this example by the use of protocols in place of clinical judgement:

‘People are very good at giving us protocols and telling us what to do, um, which I think you know, it undervalues us … that’s my job, that’s why I’m paid a lot of money, that’s why I’ve had a lot of training is to do that triaging, that managing risk, deciding where people are to go.’ (B/GP4)

The defining attributes of autonomy have been described as independence, capacity for decision making, judgement, knowledge and self-determination (Keenan, 1999). It appeared in these data extracts illustrating threats to autonomous practice, that some of these attributes were challenged – either by a recognition of the knowledge base and decision-making capacities of an alternative practitioner, or a reduction in self-determination by the use of pre-determined protocols for action.

However, there were also illustrations of what appeared to be autonomous practice as defined by these attributes:

‘I feel that this [palliative care] is one of the few specialities left where a GP who is willing to do some things can really make a difference. It’s very satisfying, I can see a patient, and I can decide what needs doing, and I can do it and see an improvement rapidly.’ (A/GP2)

‘Out of respect we do inform the GP, but if I’m, if I’m going to assess a [palliative care] patient, and I identify 8 needs, and I come away and I decide what I’m doing about those, I’m going to meet with the GP next week anyway, so I’d be saying, “oh, I went Mrs X, she’s got problems with this, I’ve referred her there, and I’ve done this, and oo oo da da da” and the GP will just say “great”; you know, so you know, I think they kind of leave me to it.’ (B/DN1)

The importance of this sense of autonomy to referral making within community palliative care is that the exercise of this self-determination often gave professionals the flexibility to respond to and make referrals in an independent manner, without necessarily having to make reference to others. What also came out clearly from the interview data, and which is reflected in some of the extracts above, was a sense of more covert practice – with professionals achieving their desired ‘autonomous’ outcomes by more clandestine ‘back door’ methods, utilised to by-pass those who might block their objectives. Descriptions were made of practices to ‘get what you wanted’ by playing games with referrals and referral
criteria. Whilst such methods may not be truly autonomous, they did show the use of judgement to achieve a desired outcome:

‘They [hospice] don’t take them in for respite, they used to, but they have moved on from that now really, but if you think a patient has respite needs, you can get them in, you just word things, and you know how to handle people really, you know what I mean. I mean they know what we are doing, but it’s just the backdoor in so to speak.’ (A/DN1)

‘District nurses are a mine of information, they know where to go, and use specialists to the maximum, to get the most out of them.’ (A/DN2)

Experience and knowledge of processes were frequently used to facilitate desired outcomes. A particular issue raised on a number of occasions was using the influence of other professionals or institutions to either bypass others’ care or influence them. For example here the hospice was used as an alternative source of medical care if the patient’s general practitioner was not supporting the nurse’s views:

‘As a district nurse my other way of getting past that is because I am like a Rottweiler, I don’t let go … I do find that if you have got a foot in the door at the hospice with a patient, if the situation with the GP unfortunately breaks down, there are other avenues to go down … that sounds like we are all playing games doesn’t it really, but sometimes that is the way.’ (B/SN2)

Examples were also given of using ‘back door’ methods to find out about patients who could benefit from care.

‘I think it’s hugely important as to which GPs you work with and you just have to work out that if you can’t get through to the GP then you would have to work out ways in which you can get them to identify these patients.’ (C/KI3)

‘I don’t think with this particular person [GP] it [referrals] will ever change, but you just have to find backdoor ways of doing it, like encouraging, er, the practice nurse to get involved, and refer on if she finds anything out. Sounds very underhand, doesn’t it, but sometimes needs must.’ (C/DN2)

There was a clear differentiation made by some respondents with regard to medical roles which they could not bypass such as prescribing, and other roles which they could autonomously and legitimately fill as a nurse, particularly if relationships with medical practitioners were strained. There was a strong undercurrent in many interviews of feelings of frustration, particularly voiced by
district nurses about general practitioners, and a sense that some relationships were adversarial rather than collegial. These issues are explored further in chapter 8, exploring inter-professional issues and their effects on referral practices.

There were different similes used for using existing systems to achieve aims covertly – ‘back door’, ‘playing games’, ‘getting what I want’. All implied staff having prior knowledge of the systems, priorities and preferences of others with whom they worked. This knowledge was then used either to bypass staff who were anticipated not to cooperate, or to purposefully use staff who were known to be sympathetic to specific aims and objectives. Whilst this was often presented as covert working, acknowledgement was also made that people were aware of this game playing, and colluded with it. Such practices could have an impact on access and referral patterns, as respondents shaped their referrals to take account of such perceptions.

These descriptions of working patterns raise questions relating to the meaning and practice of autonomy to those working in palliative care, and how it affected their referral practices. Certainly autonomy could be conceptualised as a freedom to organise their own work and caseloads, often in a way which was distant from the controls of others. Such working practices have been noted by others, with research demonstrating that district nurses interpret their roles in palliative care in different ways (Bliss, 1998), use covert practices to limit caseload sizes by adopting individual styles of caseload management and having freedom to allocate their nursing resources (Gerrish, 1999), and manage themselves either through policy or through default (Goodman, 2000). Macmillan nurses also value the autonomy they gain from being isolated from management structures (Clark et al., 2002). These freedoms may not be ‘true’ autonomy, certainly not the type of autonomous practice considered by nursing authors to be a key determinant of the progress of nursing towards professional status (Keogh, 1997; Rutty, 1998; Gerrish et al., 2003). However, they appeared to be generally valued and protected. This autonomy allowed nurses the freedom to control access to their caseloads for patients and determine the way they worked with patients.

This type of working pattern may not be genuinely autonomous but what has been called autonomous by default (Griffiths, 1996). Griffiths (1996) suggested in her
study of district nurses that this form of autonomy is possible because of the contexts of their caring; working alone, in isolation, with their work invisible to others, distant management, and with little challenge to any working practices from the colleagues with whom they worked or from general practitioners who ‘allowed’ nurses to work autonomously.

Two related concepts of autonomy appeared to be operating in this study, particularly for the nurses: ‘back door’ autonomy, where the autonomy or self-determination was gained by being able to subvert normal routines and protocols; and ‘autonomy by default’ where autonomy was gained by lack of supervision by others. Whilst these may not be considered autonomy in terms of ‘the right to self government’, they do facilitate ‘the exercise of considered, independent judgement to effect a desirable outcome’ (Keenan, 1999).

It is worth noting that autonomous practice, of whatever type, took place alongside a desire to influence the practice of others. Specialist staff, for example, may find it difficult to influence others working practices because generalists used back-door methods to work around unwanted issues, or because specialists did not have the authority to change others’ working styles. Work with clinical nurse specialists in other fields has also found this, noting that specialists used ‘persuasion’ such as training and working alongside, as well as ‘vicarious power’ such as mandatory training, guidelines endorsed by the organisation and the use of external documents which accorded with the clinical nurse specialists’ perspective (Austin et al., 2006). Such tactics are also increasingly being used to challenge some of the clinical autonomy of general practitioners, with the use of performance indicators based on evidence based protocols and guidelines increasingly being seen as a threat to clinical judgement (Exworthy et al., 2003). In this study, whilst respondents could be negative about protocols and guidelines, they appeared to be minimally used to encourage referral or other behaviours. Indeed no documentary evidence, such as policies or protocols, was collected which appeared to impact on this autonomous self-determination.

Whilst these issues of autonomy, and the way they affect practice, are not unique to community palliative care services, they appeared to have a significant impact on the way professionals viewed their roles, and hence on their referral practices.
Referral criteria and care protocols, key to palliative care policy at the time of this study (NICE, 2004), were repeatedly subverted in pursuit of back door autonomy and autonomy by default. In addition the freedoms described allowed professionals to develop individual and perhaps idiosyncratic ways of responding to referrals, making referrals and managing their case and workloads.

7.3 Ownership

Ownership is a concept which has received scant attention in healthcare. It is argued that the concept of ownership may be an inherent component of relationships between health professionals and those for whom they care (Shields et al., 2003). Dan-Cohen (2001) argues that items (or possibly patients) can be valuable precisely because they are owned – the ownership offers privileged access, affects autonomy of the owner, and can lead to the claiming of additional rights through ownership. It may be that ‘ownership’ of a patient gives an advantage to a particular professional in relationship to the claims of others, as well as with regard to issues such as decision making on behalf of patients.

In this study, the concept of ownership appeared to be closely bound to the interrelated issues of responsibility for, and relationship building with patients. A sense of responsibility towards palliative care patients was an issue which many respondents discussed. For both general practitioners and specialist doctors, this sense of responsibility could emerge because they felt their role gave them such responsibilities. This was stated clearly by a specialist doctor:

‘Well, I’m a consultant, so it’s a traditional pattern of working that you would expect from any consultant, in the sense of having overall responsibility for all patients who come in under hospice services. Um, whether I am seeing them or not, offering advice, and through consultations in clinics, and for our in-patients.’ (B/SD1)

Responsibilities towards patients and families were also apparent from the responses of general practitioners. Their sense of responsibility appeared not just to derive from their position, but because a sense of an ongoing, enduring connection with families, rather than an opportunistic relationship based on the current illness:
‘At the end of the day they’re our patients, it’s the consultant and the hospices privilege to live with them, so we’ve got to look after them, and look the family in the eye.’ (B/GP4)

General practitioners consistently state in a range of studies that they want to maintain a role caring for palliative care patients, not necessarily wishing to hand over care to other specialists (Field, 1998; Shipman et al., 2002; Lloyd-Williams et al., 2003). One reason for this may be their sense of responsibility towards their palliative care patients, citing this as one of the reasons they want to practice palliative care (Brown et al., 1998), and that their role allows them to bring personal continuity to patients’ care (Mitchell, 2002).

Each of these medical practitioners had their own sphere of responsibility and ownership – in the hospice, and providing home care. However, the comments of B/GP4 above hinted at the issues that can arise when different professionals feel a sense of responsibility or ownership toward patients. Such difficulties can be recognised by professionals:

‘I think people are sometimes reluctant to refer to us, they might be very sceptical about what we do, and that’s understandable because these people are still responsible for their patients, um, so I think part of it is education, and perhaps we need to prove ourselves that there is a bit, there is something to palliative care that patients and nurses might benefit from.’ (C/SD1)

However, as the following extended extract demonstrates, the feeling of who can be responsible for patients, and how this affected referral and care decisions for that patient can be complex. It involved staff negotiating between those with different senses of ownership and responsibility to achieve what they felt to be best care for the patient:

‘If someone is at home they are the responsibility, the key person, the key team really is the GP and the district nurse, um, if someone is in here [hospice] then I am responsible for them, and I make the decisions, and if someone’s being referred into a clinic that’s for our advice, so there is a sense of not pre-eminence but who’s taking responsibility there. But when they’re back home they go back to the GP, and sometimes if, for example, the Macmillan nurse may go and see somebody at home, they can’t prescribe, so they have a sense of a management plan that they would like to conceive for the patient. They speak to the GP who perhaps has a different view altogether, the Macmillan nurse may come back here and speak to my colleague or myself, what should they do, well, at the end of the day, we, we may have a bit of telephone dialogue with the GP, but at the end of the day...’ (B/GP4)
they are taking responsibility for that patient, and it’s not for me, unless the patient’s life was at risk [laughs] and that’s a very different banter, but if it’s just a different opinion, then it rests with them, and it’s no big deal for me. If they think one thing, but they’re not very sure then go back to the clinic, because if the doc, there are some doctors who are not comfortable taking advice from the nurse, no matter how experienced that nurse is, and they would be, feel a little more comfortable if a domiciliary visit takes place with a medic, or they come to clinic, and we are in it at that way. We try not to get into the realm of arguing.’ (B/SD1)

This highlights issues about the overlapping spheres of responsibility or territory which different professionals experienced, and concerns of overall responsibility for patients. Core to the way palliative care services ran was a sense of negotiated access. There was no automatic referral to specialist palliative care services for patients. Professionals who worked within these services were aware of this, and so were concerned to maintain confidence in their services and current referral patterns by not undermining the authority or responsibility of others, and protecting the relationships they had developed over time.

Such territorialism can be played out in the unspoken games palliative care professionals engage in relating to knowledge or ownership of the patient, and research has shown that problems have been reported when general practitioners are perceived to have greater control and ownership of the patient than specialist nurses (Street and Blackford, 2001). The sense of territory and responsibility described by professionals can have a significant impact on the way they conduct their work with others. Work with clinical nurse specialists in palliative care has found that despite specialists adopting the rhetoric that they are not the primary carer, and that they are involved in teaching, research, leadership and consultation work, most of their work continues to be focused on face to face contact with patients (Skilbeck and Seymour, 2002; Seymour et al., 2002a). It could be argued that this face to face work gives them a territory or ‘ownership’ upon which other work could be based, both giving them clinical credibility with generalists and allowing them to broker the care services provided by others.

Generalist professionals had a much greater sense of ownership, perhaps sustained by perceptions that overall responsibility for palliative care patients lay within their sphere. Ownership is often indicated by the use of possessive pronouns (Dan-Cohen, 2001), and these were frequently found in the interviews of
nurses but rarely in the interviews with doctors or allied health professionals. It was unclear why this may be so, possibly doctors tended to assume ownership because of their responsibility, not their relationships. In their talk about whether to refer patients, nurses used possessive terms frequently (items in bold are to highlight ownership terms, not respondents emphasis):

‘We keep all our palliative care clients, if, if they’ve got a poor diagnosis. I don’t, me and my team don’t hand them on to a social service carers team, because we feel that is a nursing responsibility.’ (C/DN2)

‘I was quite protective really of the palliative care patients … I certainly wouldn’t hand any of my patients over to social services or social care if they were palliative.’ (C/KI3)

‘There are not many of my patients [referred to the hospice].’ (C/SN1)

‘You don’t want to send them [palliative care patients] into hospital, because it’s like a bottomless pit, and you think, you know am I going to get my patient back.’ (B/DN1)

‘I mean we would endeavour to, to look after our own [palliative care] patients as much as we can.’ (B/DN2)

‘What I tend to say to my patients is “ring us first, and if we think that you need to be redirected to somebody else, then we will tell you or we will contact somebody else on your behalf, but give us a ring first”.’ (B/SN2)

‘I’m looked on as old fashioned then, but my [palliative care] patients are comfortable at the end of the day and that is all I am looking for. If they are not comfortable I would question why they aren’t.’ (A/DN1)

These extracts demonstrate that the use of these personal pronouns was often associated with a description of elements of ownership of patients – wanting to be the first point of contact, wanting to restrict access to the patient by others, and not wishing to refer to other services. In addition there was also a sense that this ownership ensured quality, with an assumption that the respondents own care was excellent. Many respondents openly recognised that such feelings existed, and could act to restrict patient access to a wider range of services:

‘Some of the nurses will say, “my patient, my this, my that”, and “I don’t like that service coming in, because I like to control”, it’s about control really, if you are looking at theories it’s about power and control, about, you know, their piece of their patients.’ (B/DN1)
There was also discussion about whether such a sense of ownership over patients was positive or negative:

‘I suppose ownership can be a good thing. It can be a bad thing, can’t it, some people might, some professionals might feel that well it’s my patient and I know what I’m doing, and I don’t need anybody else’s advice. Whereby others, well, yes, this is my patient and I want to do the best and I’m not sure what I’m doing here, so I’m going to seek advice. So it could work either way.’ (B/DN3)

‘I: That’s interesting, what you say about ownership, do you think there are issues of ownership in palliative care?
A/SN2: Oh most definitely, most definitely.
I: In what way?
A/SN2: I think it’s basically those that get quite attached and quite close, and I think you’ve got to learn to distance yourself from your professional to your personal ... if you just keep it on a one to one you’ve just got tunnel vision, but yeah, I still think people do, and they like that ownership, I don’t, I like to share and give it away.’

Again, variability in the way people approached palliative care and how they provided it to patients and with others is revealed in these extracts, with recognition of different ways of working either based on a sense of ‘keeping’ care to a few people, or ‘sharing’ care with a larger team.

This sense of ownership and responsibility towards patients was engendered by early referral, and maintained by keeping contact with patients, and often restricting access by other professionals. Once ownership and responsibility had been established however, this then had an impact on ongoing care – with discharge of patients more unlikely because of fears that patients would be abandoned and not cared for by others:

‘We as district nurses, I would just take them [palliative care patients] on and visit them, I would just keep contact with them really, I wouldn’t abandon them at all. A phone call once a week or a visit once a month, they do appreciate it.’ (A/DN1)

‘Strictly speaking I should be involved for six weeks and then close the case. I think I have closed about two cases in three years, just because those relationships ... it’s just that point of contact sometimes it’s important to people.’ (B/AH1)

‘It’s very difficult to discharge them [palliative care patients], because they have had contact with somebody, and there is nobody else apart from the GP that they have contact with.’ (C/SN3)
‘You know there are very few [palliative care patients] that you would actually discharge, I mean they would have to be going out of the area or in somewhere for us not to be involved any more.’ (C/DN1)

The hospice in case study B actively endeavoured to maintain contact with patients once referred by using different elements of their care provision:

‘In [hospice outpatient] clinics, we can keep an eye on them, quite a big pool of patients who are fairly stable, but who may go on to have quite difficult problems at any moment in time. So out of that pool we can keep an eye on things, seeing them every month, every two months, or even every three months ... and then they bubble out into other aspects of the team as problems arise, and then they go back into the clinic system.’ (B/SD1)

The reluctance of professionals to ‘let go’ of patients may be linked to issues of trust and control, not just about patients developing trust with professionals, but about professionals trusting others to care for ‘their’ patients, and not losing control of the care situation. There is a real tension here between ideas of ‘ownership’ of patients which promoted strong relationships between patients and professionals and promoted continuity of care, and the knowledge that some professionals were less expert and competent than others and so patients ‘owned’ by such staff could receive sub-optimal care. The impact of such judgements of the competence of staff on referral practices is discussed in chapter 8.

Ownership of patients appeared for many to be intimately bound to the relationships which professionals form with palliative care patients. Whilst patients did not discuss concepts of ownership, they did frequently refer to the relationships they developed with professionals. Many staff, but particularly nurses, appeared to deliberately seek to develop a relationship with patients and their families. Such relationship building appeared critical to the way they approached the provision of palliative care to patients and families, and was the focus of much discussion relating to issues of timing of referrals, patterns of working and onward referrals, responsibilities towards patients, and care quality. These issues are therefore discussed in more depth.
Building a relationship with patients and families appears to be central to the way many professionals provide and conceptualise community palliative care services. The importance of ‘knowing the patient’ through such a relationship and its value as perceived by patients (McLoughlin, 2002; Carline et al., 2003; Grande et al., 2004), nurses (Radwin, 1996; Luker et al., 2000; Wright, 2002; Speed and Luker, 2004; Griffiths et al., 2006) and doctors (May et al., 2004) is clear from others’ research. This section explores how the professionals in this study conceptualised relationship building, and discusses the perceived impact of such a relationship on referral and access issues. It is specifically discussed in this section because it appeared to be the medium through which other care was given, essential to the development of ownership over or responsibility for patients, which then impacted on referral choices.

For most referral–driven professionals, the timing of the referral was key to the quality of the relationship they could build with the patient and their family. It was important to many professionals that they received a referral as early as possible to facilitate the building of a relationship over time. The timing of referrals has been discussed in more detail already in chapter 6, but issues specifically related to relationship building are explored here.

It was apparent that early referrals were made by some staff explicitly for the purpose of relationship building for future care, not just for immediate needs, a finding which concurs with earlier work (Mcilfatrick and Curran, 1999; Luker et al., 2000). It was not necessarily the case that the relationship was immediately therapeutic, but that it had the potential to facilitate future care, as for example in this extract from case study C:

‘I: You said you refer to them fairly early [to district nurses], can you define what you mean by fairly early, or what sort of stage would you be thinking of referring [palliative care] patients?
C/GP6: If they’ve got an immediate nursing need, particularly if they have got stomas, and stuff like that, but also if it is very clear that this patient is going to be needing a lot of care over the coming days, months or sometimes years, so that they develop a relationship, and I think that’s really important.’
This understanding of the purpose of the referral was also shared by those receiving referrals:

‘I think district nursing services provide a good service, because, you know, if they are referred to us early enough, I think, that’s the best way, because then we can build up a relationship with them, the family, if there are any.’ (C/DN1)

‘I am afraid that we don’t get involved sometimes that early, and I feel that’s a downfall because we need to know the patients much sooner before, you know, before the disease gets progressive.’ (C/DN5)

These feelings were also shared across the other case study sites:

‘I think there’s a need to develop relationships, and so I think palliative care, general practice, family care, palliative care, starts at a earlier stage, and because I think to offer any kind of good palliative care I think the first thing you need to do is develop ground rules that are inherent in a good relationship, about trust, about sincerity, about being able to understand the nature of the information and not just the content of the information, and the nuances of communication … we’re getting district nurses much more connected with the patient early on and keeping them in the loop really…’ (A/GP3)

‘If district nurses are involved from the beginning, you get to know them, so by the time the end comes you’ve got to know the family, you’ve got to know the all the little ins and outs of relationships, but when you just go in at the end stage and the families are all upset about it all, it’s very difficult to form a relationship in the last few days or weeks of life.’ (A/DN4)

There was a perception of balance – an understanding that referrals were necessary to develop this relationship, but that time and other constraints negated against a blanket referral policy:

‘At which point do you refer them? Do you wait until there is a crisis, and then they come into the team fresh, and you don’t know anyone, you don’t know their background, you don’t know their family dynamics, you don’t know what makes that patient tick, and you’re dealing with an existing crisis, and in a much harder, in a less easy manner than we would do if we already know that patient, so there’s quite a dilemma between an early referral in anticipation of problems, and not referring everybody.’ (B/SD1)

These data extracts also reveal that what appeared important was not just developing a relationship with the patient, but getting to know the family and their unique circumstances. Such knowledge was felt to assist professionals in dealing with patients and their families, in what could be a difficult home situation. It may
be that such relationship building is particularly important to staff in the community because of the difficulties of being a visitor in someone’s home.

Whilst there was significant support for the concept of relationship building, there were potential problems with such relationships. This may be because the relationship which developed was poor or had a difficult history:

‘The problems could arise obviously if during that long course of history then say that the cancer diagnosis has been delayed or whatever, that you have actually maybe missed something, then that could very much obviously affect your ability to be able to offer good palliative care, but I suppose that is, if something goes wrong and you lose the trust in that relationship and it affects your ability to provide whatever care afterwards.’ (C/GP5)

Conversely, one respondent actually felt that developing a relationship that was too close to the patient or family might not be advantageous because it affected the quality of communication. In this extract, concerns were discussed that patients may be circumspect in their communications with valued professionals or accept care they were not satisfied with because they did not wish to upset the professional involved:

‘Sometimes when a nurse is going in on a daily basis all the time and doing, you do become like, with a lot of patients, like part of the family, so even though you have a really good relationship with them sometimes they may not be happy with something you’ve done, or but feel, “I don’t want to upset them, because they are giving me this care”.’ (C/DN2)

In addition some respondents also dismissed the importance of long term relationships with professionals other than themselves:

‘I: Do you think it makes a difference to the patient that the GP is somebody that they have known …
C/DN3: For a long time? I’m not sure because I think it, I mean sometimes they have got a new GP, and the new GP has just joined the practice, the old one, and if there is that rapport with them, I don’t think it really matters.’

‘I don’t think for them [patients] it makes one jot of difference who we are as long as we are doing the job, but I think as professionals we prefer them to know who we are and what we are doing there.’ (B/SN2)

It appears therefore that for some professionals, the relationship was very much about the professionals’ needs and perspectives rather than the patients’.
Despite these caveats, there was almost universal acceptance of the importance of the development of good relationships between patient and professional. Professionals argued that such relationships had a number of advantages: facilitating contact between patient and professional; allowing the professional to work more closely with the family; increasing professionals’ awareness of patients’ needs and preferences; facilitating the development of trust; aiding communication; alleviating patient and family stress and anxiety; and making a ‘good death’ more possible. These understandings of relationship building are illustrated and highlighted in the data extracts below. The emphasis is to highlight the relationship building issues, not the respondents’ emphasis:

‘Just, well I think it makes your life easier, the way you care for somebody, because you understand the things they’ll accept and the things they won’t, things like, will they have a commode and, you know, you can talk them round when you know them, because you can say, yes I know, but this will be better because of this, and you understand the family dynamics, you know, you know that one member of the family, one daughter is going to get really upset, so you wouldn’t talk to her about such things, you’d talk to another member, and then they could relay it down, and you find out who’s the head of the family, because there’s usually one who’s the main carer, um, and then the others kind of er, you know, work round her or him. I think that’s how it, and they get to know you, they get to know you as people, you know, as well, and they learn to trust you. Because if they’ve, if you’ve gone through with them and things have worked out, and you’ve done things as you’ve promised and that, they’ll learn to trust you.’ (A/DN4)

‘I think it’s [developing a relationship] terribly important because if the patient is relaxed and trusts their nurse, their doctor, their Consultant, their, the people around them, and particularly the people around are with them frequently, then it makes them accept what happens much more readily, um they’re more relaxed therefore they, if they’re anxious, and of course if they’re in pain, but if they’re anxious and rejecting their illness, because quite often they are to start with anyway, um, and they’re rejecting all the people around them, then I think it makes a much, much more stormy course, you know they’re going to have a stormy course a lot of the time anyway, but if you know the people who are coming in, and you know that they will listen to you, they will take care of you, and you’ve met them before, it’s not a new face everyday, um, then I think the progression of the illness is much better, and the death is much better, if you can say that, it makes it that bit easier for them and their own particular care, so I feel that’s, that’s one of the things about primary care you’ve got that long term relationship, and it must develop with the nurses as well as the doctors, and that’s why I think, because I think you can have a, you can have a very good death, and, and if you don’t have a good death then the effect on the people who are left, and I see it so often are, just go on and on and on they pass that to their own children and their own family, and it makes death much more difficult to accept.’(C/GP6)
Such benefits of relationship building have been found to be important by others, and have been suggested as the essential antecedent of high quality palliative care, facilitating communication and holistic competent care (Luker et al., 2000; Hamilton and McDowell, 2004; Mok and Chiu, 2004; de Haes and Teunissen, 2005).

There was also an understanding that developing such a trusting relationship was not only good for patient care, but that it had two impacts on the professionals themselves – it made their care easier to provide, and it was a source of much job satisfaction:

‘I think a lot of the rewards … is those really good relationships that develop really quickly with the patients and their families, and I think a lot of the reward and the job satisfaction comes from that.’ (B/AH1)

‘I mean it’s lovely, isn’t it, to go away, if you’re a nurse, to deliver palliative care is what you’re all about, isn’t it, to make sure that that person’s end of life is as comfortable and as smooth as possible, and you know the family, and you know the carers, and you, know ideally, from my point of view, I would like to deliver as much of that as our team can, and that’s lovely.’ (B/DN2)

These statements concur with the research referred to earlier on the importance of relationship building to nurses, where ‘personal knowing’ is valued, allowing the patient to ‘matter’ to the nurse (White, 1995). It is argued that such ‘knowing’ is both valued by nurses, and is relevant to decision making as interventions (including referrals) are chosen so that the patient is treated as a unique individual (Radwin, 1996). The importance of such a relationship to professionals is particularly highlighted in a recent phenomenological study about being a palliative care nurse for people with heart failure (Brännström et al., 2005). Respondents in this study emphasise participating in patient’s everyday lives, and discuss how good it felt to be let into someone else’s life. They also feel this gives them enormous freedom to nurse in the way they wanted, and control over who could care for ‘their’ patient. The importance of the relationship to nurses is highlighted, and its potential impact on the way they care for patients, including how they interact with other professionals and ‘allow’ them to care for ‘their’ patients. Building a relationship with patients is therefore strongly linked here with the sense of ownership discussed earlier.
Recent research suggests that district nurses are changing in their patterns of knowing the patient, affected by the loss of opportunities to know people through providing hygiene and social care (Speed and Luker, 2004). Speed and Luker (2004) suggest that nurses do not ‘know’ patients, but know about them, focusing on what they called ‘techno-care’ whilst others did ‘the social’. McGarry (2003) questions whether the demands on district nurses to provide technical care have had an adverse effect on workloads and the abilities to form relationships with patients. It does appear from the data presented here, that palliative care patients may be an exception to this trend, and be an area of caring where professionals feel ‘allowed’ to still develop ‘personal knowing’. The special or different nature of caring for palliative care patients is identified by other authors (Griffiths, 1997; Goodman et al., 1998), and is explored later in this chapter.

Few specialist staff talked as explicitly about relationship building. This may be because they had less opportunity to build relationships if they were referred later in a patients’ illness. It may also be because generalists prized relationship building more because of the ‘status’ it gave them with other professionals, a need which may be met in specialists by the expertise or time they had to offer patients rather than a relationship.

The importance of relationship building between patients, families and professionals was also recognised by many of the patients interviewed. Many shared the professional’s viewpoint that developing an immediate relationship with staff, often based on easy going humour, characterised as ‘having a laugh’, eased visits, helped them to get to know staff, and aided communication:

“She is a good friend, [B/SN3], she has, she has become really close. You can chat with her, you can say, you can have a laugh with her, say what you want.” (B/P2)

“I’ve got to know them pretty well [district nurses] … so they’ll have a laugh with you, and they are pretty good and that.” (C/P3)

However, some also recognised and were open enough to discuss the fact that this rapport and relationship would facilitate care in the future:

“It’s so helpful that you have the rapport, because now we’re at this stage, it would be more difficult to open up to strangers … because when the time
comes when I need them more, which I’m going to, I won’t be having strangers in, and I don’t think that would be very nice for me but it definitely wouldn’t be very nice for [name of partner], ‘cos although he hasn’t taken advantage of the fact that the district nurses have said they’re there for him, he’s met them, he’s been, he’s had a laugh with them, so they’re not going to be strangers’ (B/P1)

However, where contact was more limited, this appeared to affect the way patients used or contacted professionals:

‘We had a Macmillan nurse up at the very beginning, and she chatted for a bit and she left and she said she would leave me her phone number, she left the phone number and said get in touch if you have any problems, but we never saw her again, we never rung her, and we never saw her or asked for her.’ (C/P5)

It appeared that many of the reasons for relationship building expounded by health care professionals were also shared by the patients for whom they cared. This concurs with the work of others. It has been found that patients value interpersonal continuity in primary care because it gives a sense of security, based on feelings of coherence, confidence in care, a trusting relationship and accessibility (von Bültzingslöwen et al., 2006). Research with dying patients found that they value emotional support and personalisation (Wenrich et al., 2003), and are satisfied with humanistic care that responds to individual situations (Hopkinson and Hallett, 2001). A cautionary note is sounded by Chapple et al. (2005), who found that whilst patients valued emotional support from specialist palliative care nurses, they sometimes did not want this, and there was no mention of developing a relationship with such nurses. Patients in their study talked equally about advice on practical matters, information giving and advice with symptoms.

It appeared that professionals developed relationships for reasons which benefited patients as well as themselves. Patients and professionals were therefore investing time and energy in relationship building. What was apparent from the patient interviews was that they generally only described investing in a relationship with one professional group – usually the professionals with most regular contact with them. Relationship building appears to have mutual benefits to both patient and professional, and has been argued to be a method which manages relations between professionals and patients, maintaining social order as well as advancing personal, professional and organisational aspirations (Li, 2004).
Relationship building was important to understanding how and why patients access community palliative care services for two reasons. First, getting to know patients was in itself ‘work’, and therefore is in its own right a reason why patients may be referred to services (May, 1992). This was recognised by respondents in this study, who worked to facilitate early referrals so that relationships may be built for the future. Second, the very act of building a relationship and investing time and energy in it affected the way professionals perceived their role with patients, and can lead to feelings of ownership, which can lead to professionals actively restricting the number of other professionals to whom they will refer.

7.4 Expertise in palliative care

How expertise in palliative care affected referrals is explored in this section. For clarity, it looks not only at the expertise of the referring professional, but also the perceived expertise of others who could provide care, and how these factors interacted to affect referral processes.

Key to referral processes was a self assessment of professionals’ own capabilities and limits of expertise, and their judgement of the expertise of the person to whom they were referring. Where respondents felt they could offer expertise to patients or where they perceived others could not offer considerable additional expertise, then referrals appeared less likely to take place:

‘We’ve got quite a lot of experience so it’s only when I think that people feel that it’s getting beyond them, and beyond me, and beyond everybody else’s expertise that we think, “right, actually now I think we need to ask somebody else’s help and advice”.’ (B/DN1)

Such triggers for referral decision making are also found in research investigating general practitioners referrals for general psychological problems, where referral decisions were made when general practitioners felt they had reached the limits of their capabilities for treating a particular problem (Sigel and Leiper, 2004).

The appraisal of others’ expertise was critically related to a judgement of prior competence, and the way past referrals had been handled:
‘I think my GPs have had a problem with the Macmillan Nurses in the past, I don’t think they particularly liked the way she worked … now the rest of the staff in [Case study A] don’t use them [Macmillan Nurses] very much really. Quite often they were never there to give the advice that you wanted.’ (A/DN1)

Staff appeared to make critical judgements, considering issues such as their appraisal of the other professional’s expertise, with their own and the patient’s needs in a particular situation to judge both the costs and the potential added value of a referral. Specialists were aware of these issues, but in a referral driven service appeared disempowered to offer knowledge and expertise without an explicit invitation.

Expertise in palliative care could be affected by different issues – but two core and interrelated factors were the professionals’ educational preparation for the role, and their interest in palliative care provision. Respondents identified significant variation in both their own and others’ educational preparation for the roles they fulfilled. Underpinning this variation in preparation was the awareness that educational preparation to deliver palliative care as a generalist was not a mandatory element of post-registration training, and so could be dependent on the individual’s own interest in the subject as well as the opportunities afforded to them. This interest could both affect their desire to attend educational sessions, and the way they used knowledge gained:

‘District nurses have interests in different things, don’t they, and so it’s [educational opportunities] what you try and access yourself.’ (C/DN4)

‘Sometimes people think about professional activity as a sort of model of, you have some information, you go and do it. But actually our behaviour is very much determined by our thoughts and feelings, and our own experiences, and our levels of confidence in all those things.’ (C/GP2)

‘Most of them [GPs] from what I’m aware of, there’s very little knowledge in palliative care. You may get some who are very interested, the odd few, and you’d be lucky to have those within your practice that you’re working for, um, but the majority have an interest but they don’t always have the knowledge.’ (A/SN2)

Some respondents felt that the opportunities offered to professionals to update themselves on palliative care issues were available on an ad-hoc or unplanned basis or taken up in a patchy manner. This meant that the baseline knowledge and skills of such professionals were very variable:
'I think you need to look back at GPs. And how do we educate a GP, how am I educated? What protected time am I delivered to, do I really get to learn about palliative care? Zero! What protected time do I get to actually learn myself? None!' (B/GP4)

‘When I went to see the district nurses I asked at that point as to around academic qualifications in palliative care, and I was quite surprised how few really even have the old ENB931s, care of the dying, and we’re talking team leaders as well … so I was surprised coming to [case study A] to find it wasn’t even a baseline really, um, and a lot of the staff were saying that they’d attended maybe one or two days of the Macmillan’s in-house training … I’m not truly certain of the knowledge and skills of the staff.’ (A/SN4)

However, when educational opportunities were offered to and taken up by staff, there could be confusion about the objectives and outcomes of such preparation:

‘Increasingly, a number of the district nurses have been on, I think it’s changed now, the course, the 931 care of the dying patient and family, I think it’s principles of palliative care now, and I think the managers saw that the district nurses have similar skills to ourselves because they have done this core foundation course in the care of the dying … there are one or two practices where the GPs have so much confidence in their district nurses they don’t feel the need for specialist input.’ (B/SN1)

Research into the educational preparation of generalists to facilitate their competence in providing palliative care reveals that their preparation can be patchy, with the issue of reluctant or disinterested learners highlighted (Hillier and Wee, 2001). Questionnaire studies show that some general practitioners receive little training in palliative care, although they receive more than junior doctors (Barclay et al., 1997; Barclay et al., 2003). General practitioners also request that very specific issues are addressed in their palliative care education, asking almost exclusively for symptom control education in one study (Shipman et al., 2001). Another focus group study reveals desires for education in communication skills as well as the dominance of symptom control issues (Meijler et al., 2005). This may mean that they are less likely to attend educational sessions which do not address such issues.

The needs of district nurses for additional educational preparation in palliative care have also been recognised, with widespread educational opportunities during the conduct of this study being available through the cancer networks as a result of additional government funding which aimed to increase the capacity of nurses to
provide good palliative care in community settings (Department of Health, 2001; Addington-Hall et al., 2006). Evaluation of these programmes demonstrates nurses have increased confidence in their palliative care competencies, with topics relating to caring for those undergoing chemotherapy, managing cancer care emergencies and pain and symptom control being the most wanted (Hughes et al., 2006; Addington-Hall et al., 2006). Such educational programmes may increase referrals to specialist palliative care services (Addington-Hall et al., 2006), an effect hypothesised by other authors (Friedman et al., 2002; Schim et al., 2000).

This disparity in educational preparation particularly highlighted some tensions between specialists and generalists. When there is such variation in the skills and knowledge of generalists, it is unsurprising that some felt that their preparation makes their practice close enough to that of specialists for referrals to such services to be unnecessary:

‘I think training of general practice district nurses in palliative care, which is sort of probably a lot better than it was, but should be high up the agenda, because I think that a lot of these services can and should be offered by well trained generalists, rather than devolving to specialist palliative care teams.’ (B/GP3)

‘Because we’re all quite experienced here it hasn’t really affected us that much [lack of Macmillan nursing services]. But I do know in other teams where they’re not as experienced it’s affected them more … we didn’t really know that there weren’t any, we hadn’t really noticed, because we don’t you know … refer.’ (A/DN4)

‘A/SN1: Never needed to refer to the …
I: To the community Macmillan nurses?
A/SN1: Never needed to refer for psychological support because I’m trained, so that’s not a need.’

This issue was clearly recognised by specialists, who were well aware both of the inherent variability in practice of those with whom they worked, and the impact this had on peoples’ perceptions of their own abilities and the impact on referrals:

‘One of the criticisms especially about specialism for me is that people don’t tend to refer on, and they try to manage it themselves, and they try to be the expert.’ (B/SN3)

Again there was variability in practice, with other professionals reporting that they were happy to refer on to access the expertise of others. This was also reported in a study of continence nurses, where community nurses were happy with the
specialist nurse role as they felt they did not have appropriate depth of knowledge (Austin et al., 2006). It may be that palliative care is perceived as a different type of speciality because of the ‘status’ of palliative care patients, and the frequency with which district nurses care for such patients.

Perceptions of expertise therefore appeared to affect referral practices, with those who felt themselves to have sufficient expertise in a particular area reporting that they were less likely to refer on to specialist staff. However, this perception of expertise was not necessarily recognised by the specialist staff, who questioned the basis of this expertise, and hence the appropriateness of not referring patients.

7.5 Workload issues

Professionals’ perceptions of their own case and workloads could significantly affect the way they made and responded to referrals. This issue was primarily discussed by the nurses, particularly district nurses, within the study, with an appreciation of nurse workload constraints discussed by others. Two interrelated topics are discussed; controlling case and workloads and having and buying time.

Controlling case and workloads

District nurses have long argued that they are a ‘ward without walls’, with few external limitations on their case or workloads (Audit Commission, 1999). Their perception of their service as flexible, responsive, yet sometimes perhaps a ‘dumping ground’ referral destination appeared to affect the way they see themselves, and others see them. This was encapsulated by a comment from a general practitioner:

‘I: How would you describe the district nurses’ role in palliative care?  
B/GP1: Oh, they are the people at the sharp end doing all the things that nobody else wants to do.’

This perception of district nurses was also shared by a specialist nurse within the same case study site:

‘District nurses obviously take on board everything that is thrown at them and they are not allowed to say no.’ (B/SN2)
This perception of the response of district nurses to referrals and workload was not just found within case study B, as these district nurses in case study A described:

‘Everything is thrown at us as District Nurses [discussing impact of the GSF]. We’ve absorbed the extra work with difficulty, you’ve just got to. We have a major shortage of nurses, but we just absorb it, always absorbed it. We ring down to other district nurse teams for help, you’ve just got to manage … GPs are more assertive about not taking on extra work, they have other things to do.’ (A/DN2)

‘In the past, social services somehow were able to give an hour a day to patients in their last stages of life, say in the last six months or so, for hygiene … it was withdrawn … so then that put a lot of pressure on district nurses because there was nobody else to do it, they didn’t kind of consult, they just withdrew it.’ (A/DN4)

There was a sense that district nurses found it more difficult than other professionals to refuse to provide care, and appeared in the above extracts to passively accept work. They sometimes actively worked to fill gaps in service they identified, because they felt there would be nobody else meeting that need. They were described as doing the things no one else wants to do, taking on board everything, and absorbing all extra work. This echoes earlier work which found that district nurses filled the gaps when service provision was lacking (Griffiths, 1998). Some authors have related this to lack of explicit referral criteria for district nursing services, discussed in chapter 6.

This characteristic of finding it hard to refuse referrals meant that district nurses found strategies to cope with what could be onerous workloads:

‘If you have got no staff, then you have got quite a high workload proportion, and then obviously you know you have to then look at your workload, and re-assess it then, but I would not say that we would shut our doors on palliative care patients, or any patients particularly, we would just try and manage it as best we could.’ (C/DN1)

‘C/DN2: If you get in an awful lot of people who are at the same stage [of their palliative illness], which can happen, that can increase your workload level because obviously it’s more intensive, needs more time, so yeah, it can influence your workload.
I: And so how do you manage that?
C/DN2: ‘You just do, nurses just do don’t they.’
There was a distinct sense of pride from district nurses when they were discussing such responses to referrals and workload pressures. They compared themselves favourably to those professionals or service providers who did restrict services. They balanced their workload by juggling strategies, rarely abandoning patients, but sometimes working late or restricting the time they spent with individual patients. They described fluid strategies such as ‘absorbing’ the work, ‘finding the time’ and that the workload ‘balanced itself’ without describing a formal management strategy to achieve this ability to expand their service to meet perceived needs:

‘I mean at the end of the day if we’ve got to see a palliative care patient and we haven’t got the staff we’ll still do it, might take us, might not get back here until really late, but we don’t start crossing people off any more … all our patients are patients that we have to see ‘cos we are busy so we don’t just put people on that we don’t really need to see.’ (C/DN3)

An appreciation of the changeable and unpredictable nature of the workload seemed to facilitate this approach because the nurses knew that the times of increased workload were variable rather than constant.

‘District nursing is really funny because you could, you can be absolutely pulled out one week, and quieter the next.’ (B/DN2)

‘We used to expand and expand, but it always works itself out, I don’t know why, but it does. You know if you get 9 referrals you might find all of a sudden two people have gone into hospital, or somebody has died, and somebody has died the next weekend, and it has just got a sort of funny way of sort of levelling itself out, almost.’ (C/SN1)

This nurse then went on to discuss the fact that she would be unhappy with caseload controls or with somebody else involved in monitoring or allocating referrals:

‘I don’t know whether I would like it though if somebody did cap your referrals, because I know at the hospice when [name] used to work at the hospice when she was based at [neighbouring PCT], and then you would have a medical director or somebody looking through referrals, and then deciding who got what and how many they got. And they didn’t, you don’t worry if you don’t know there is a big pile of referrals there. But I don’t know, I don’t think I would like somebody else making decisions like that. About whether I could cope or whether I was able, you know, to take on new referrals or not discharge them or whatever.’ (C/SN1)
These comments relate to earlier discussions about autonomy and responsibility for referrals, with C/SN1 identifying that it was her personal responsibility for referrals which motivated her response to them, whereas a more formal team allocation would not elicit this ownership of and responsibility towards the referred patient. The perceptions of nurses that they managed themselves (discussed in section 7.1) can also be contrasted to this sense of accepting referrals and filling gaps. It could be argued that being a ‘dumping ground’ referral destination does not indicate autonomous practice. However, it was the nurse’s response to these referrals which they felt they had control over, rather than the receipt of the referral.

There were some respondents, particularly in case study A, who reported a different response to referrals, mediated by their perception of a stretched, under funded workforce.

‘And then we don’t offer too much to begin with, because if you offer too much to start off with when they’re, really do become dependent there’s nothing left to offer them, and that’s when they feel it … It does, makes it very hard, when we don’t have the wherewithal to go in every day to these people … you know, with the best will in the world, we just don’t have the wherewithal to take on patients who’ve got 7 months left, even if they may need that little bit of help.’ (A/DN3)

What did not seem to be an issue was that of general practitioners’ workloads affecting their care or response to referrals. Whilst reference was made by them to work pressures, it did not appear to affect their workload or response to referrals in the way described above by nurses. However, they did refer to creating time by making referrals, and this is discussed next.

**Having and buying the time**

In the often pressured environment of primary care, time was a precious commodity. Being perceived as having the time for palliative care could be very important in the way that professional services were used and appreciated by others:

‘They [patients] tend to like them [district nurses], because they, they, because I think, they do tend to be people who’ll spend some time with them, and they don’t see themselves as being, I think they probably see GPs and Macmillan...’
nurses as being professionals and not worth their while, and so I think a lot of stuff, we get a lot of fears and um, the underlying problems from our district nurses who will sit down and talk to people a lot more than we probably do without an agenda.' (B/GP1)

McIlfatrick and Curran (2000) identify time as the second most important factor affecting the provision of palliative care. In their study and those of Austin et al. (2000) and Griffiths (1997), district nurses identify that they prioritise giving time to palliative care patients. In this study it was also a source of satisfaction and pride to many professionals that they prioritised palliative care patients, to ensure that they did have the time within a busy working day:

‘Although we have been really short staffed we are proud of ourselves that we have been able to deliver high standards of palliative care, but consequently other things have had to go in order to do that.’ (A/DN5)

However, in contrast to the perception of the general practitioner above, many staff perceived that time constraints were a significant factor in their pressured workloads and their inabilities to provide the type of care they would like:

‘I think because district nurses cover, you’re like a Jack of all trades, you know a little bit about a lot of things, and we just felt that because palliative care is so personal and so emotional that we don’t always have the time facility to provide that.’ (B/DN4)

‘I: Why is there a hospice at home service? B/SN2: Because it was seen that district nurses alone could not offer that service sufficiently with the time constraints that we have, yes, we can go in, in the morning, we can give a patient a wash, we can change the bed, we can do that, but we are rushing, we have not really because of all the other initiatives that are out in the community, all the initiatives about early discharge, preventing discharge, as district nurses we are taking on more and more work.’

‘I know the district nurses have less and less time to do anything other than physical things because, for example, I did used to have an elderly care team of dedicated nurses, but they have been removed. So you know they are all expected to do more things.’ (C/GP3)

These time constraints meant that referrals to other services could be prompted to both relieve the workload of the referrer, and to ensure that the patient got the time required to address their needs:

‘I think sometimes the Macmillan nurse also is, is a better person than a district nurse because they have a lot more time in which to spend where erm,
I think most district nurses, would, would put the patient first and would probably spend a long time with that patient, but then unfortunately other patients then, you know, I hate to say it, do tend to suffer, because you’ve got to make up that time somewhere.’ (C/DN2)

This perception of specialist palliative care professionals having more time was endorsed both by other specialists and generalists:

‘As we spend our lives dealing with palliative care problems, and um, and we have a lot longer in terms of clinics. A lot longer to talk to patients and families.’ (B/SD1)

Discussion of the concept of using specialist services to provide more time for generalist staff and patients was particularly found in case study C:

‘I think it means we make more use of our Macmillan nurse, who has got a bit more time, but not a lot more time than we have in talking to patients and making sure that other support services are plugged in.’ (C/GP1)

‘Can sit down and chat more than we can because we don’t have the time to do that, we have got other nursing things like dressings and insulins or whatever, whereas the Macmillan nurse would sort of have, spend a bit more time with those patients which we probably wouldn’t be able to do.’ (C/DN5)

This perception was supported by the specialist nurses in case study C:

‘I get to sit down and have a cup of tea and a biscuit. And I don’t look as rushed and hurried as the district nurse … it gives them [the patient] the opportunity then to sit and relax and think about what they’re going to tell you, whereas the district nurse’ll say “well come on, lets have a look at it”, and, “I’ll see you tomorrow”, and sometimes it’s the attitude and it may just be the briskness of their voice that, that the patient is aware that this person is in a rush.’ (C/SN3)

The perception that nurses had more time to spend with patients was also identified in a series of focus groups with doctors discussing palliative care (Hibbert et al., 2003; Hanratty et al., 2006). Aitken (2006) also identified that district nurses’ time deficits triggered referrals to specialist care. In this study generalists observed that patients identified this difference between the time spent with them by specialist and generalist professionals:

‘They were quite aware of when the Macmillan went out, how much longer they spent there, how much more in-depth they went into everything,
whereas, as a district nurse we would go in and maybe be twenty minutes, half an hour and then come away again.’ (B/DN2)

Given that, as highlighted above, referrals to specialist services were not always made to access their additional expertise, being perceived as a service which was likely to offer more time to patients may promote referrals into the services. It appeared that maintaining the perceptions of others that specialists ‘have the time’ is important to facilitating referrals. There appears to be a symbiotic relationship between specialist professionals having time to offer to generalists, and generalists taking on the time consuming role of filtering referrals to specialists discussed in chapter 6.

However, lack of time may also be a convenient way to explain an avoidance of care by some professionals. Seale (1992) identifies that district nurses felt they had a lack of time to care for terminally ill patients, particularly to spend time with them in a supportive way. However, when discussing specific examples, district nurses in his study did feel that they had enough time to care, so there was a discrepancy between their perceptions of an ideal situation and the reality of what was necessary or that they had the skills for. There is much evidence that many professionals lack the skills to effectively communicate with patients (Maguire, 1999; Gysels et al., 2004; de Haes and Teunissen, 2005), and that one reason for avoiding in-depth communication is the time that it would take were psychological issues revealed or strong emotions displayed (Maguire, 1999). There may be complex undisclosed reasons for time being cited as a reason for referral to others, with not only the reality of a stretched service triggering referrals, but also concerns about having sufficient skills to provide time-consuming and difficult psychological care to patients.

7.6 Status of palliative care work

Caring for palliative care patients appeared to be a priority for many, since despite their description of it being emotionally draining it had the potential to offer them rewards in their professional lives. Respondents described the priority given to palliative care patients, discussing incidents when they extended their normal range of caring behaviours for those patients:
‘My time that allows me to go and see these [palliative care] patients, the whole practice knows about it, and there are major times when I need to drop surgery, and someone has to, you know, back me up.’ (A/GP3)

‘I quite often, if people are going terminal, particularly in the last few days, I’ll let them have my home number, and um, my message is, here’s my home number, give us a ring if you’re having problems.’ (B/GP4)

‘Maybe, even if you think well this is actually going to be only a short period of time as well, I think you would probably access the proper route, I think sometimes you break the rules a bit for palliative care patients, and bend the rules, well we certainly did.’ (C/KI3)

This echoes the findings of Grande et al. (2004) who found examples of general practitioners and district nurses doing things over and above the normal course of work for palliative care patients such as giving out home phone numbers and staying beyond hours of duty. The rationale for many of these behaviours centred on the way palliative care work was considered to exemplify the best aspects of their profession, and the job satisfaction that this work gave them:

‘But that’s really the exemplar of district nursing, palliative care, and it’s our best practice area. Um, the rest is like wound management, bowel management and things like that, and moving and handling and all sorts of other things, but you know, the, but it’s surprising where the smaller percentage takes up the greatest time, isn’t it? So, you know, I could spend all day trying to sort out somebody for palliative care in terms of symptom control.’ (B/DN1)

‘The district nurses have kept palliative care [rather than handing patients to social care services], it’s been something that they view as being very important. They view it as their bread and butter of being a district nurse, which in many respects is quite a traditional view of palliative care.’ (A/SN4)

Respondents, particularly nurses, talked about their passion for palliative care patients:

‘Yeah, the fact that we haven’t got enough staff, yes, will have a knock on effect, because it will roll, we’re all passionate in [Case study A] about our palliative patients, and we’re all protective of them, but it’s bound to have a knock on effect, at that time, if you cannot give the care you want to give.’ (A/DN3)

‘I am sure you will find that most district nurses are quite passionate about palliative care and, um, wanting to deliver the best care really.’ (B/DN2)
‘I just feel quite passionate about my palliative care patients, so I think it would make me a bit cross if I found out that people were not giving them the best care really.’ (C/KI3)

They talked specifically about the personal rewards they gained from caring for palliative care patients:

‘I think it’s something that is nice to be involved in actually, because, it’s not, it’s very gratifying in some ways. I mean it can be quite draining obviously as well and things, but if you offer good palliative care, and the family are supporting the patients, and everybody knows that basically that is the patients wishes, it can actually be very satisfying work as well.’ (C/GP5)

‘If we achieve as a team somebody who dies peacefully at home, it’s such a feeling of great satisfaction, that you think it was worth all that, it was worth all them phone calls, it was worth swearing like trooper when I got home, it was worth all the hassle and the intervention and those hours spent extra working through my lunchtimes, and all the rest of it, so that that patient got what they wanted, so it’s a good feeling.’ (B/DN1)

Such rewards are also found in a study of hospital palliative care nurses, where they describe both the emotionally intense and draining aspect of the work, but also the incredible rewards of meeting people who gave back so much of themselves (Sandgren et al., 2006). District nurses often define their work by reference to palliative care. Where district nurses contrast the care of palliative care patients to that of other patients they consistently refer to palliative care patients as being the ones they prioritised and still had time to provide ‘basic’ nursing care for (Austin et al., 2000). Research conducted in the 1990s when elements of care previously defined as nursing had recently been devolved to social care, found that district nurses still practiced the ‘older’ style of care with palliative care patients, the terminal nature of the illness sanctioning nursing activities normally seen as social care (Griffiths, 1997; Goodman et al., 1998).

Caring for palliative care patients however was not always upbeat and positive, and many staff acknowledged that whilst caring for these patients was rewarding, it also has the potential to be difficult, emotionally challenging and draining:

‘I think they [specialist palliative care nurses] get a buzz out of troubleshooting, however there is a balance, because we all need some easy patients to see, if you spend your day dealing with really difficult problems, either symptom control problems or somebody facing dying, or difficult family dynamics then it’s an absolutely exhausting business.’ (B/SD1)
Some staff appeared to find it difficult to handle the emotional situations they found
themselves in whilst caring for palliative care patients and for some it was a trigger
for them to refer patients on to others:

‘I think of our needs, and you know, if we’re stressed and wound up we’re
more likely to refer on.’ (B/GP4)

‘When you see it as like an untimely death, psychological problems seem to
be, is that a general assertion, I don’t know, it always seems traumatic, more
traumatic the younger the person is, and if there’s children involved, and
sometimes we, you know when it’s like that, you need to have somebody else
in as well, because we’ve become bogged down sometimes, you know, so
sort of like they offer support to us really.’ (B/DN2)

Similar referral triggers are also described in general practitioner referrals for
patients with minor mental illness. General practitioners could be proactive
‘referring to’, but also ‘referring away’ for emotive, non-rational reasons in
situations they found difficult to manage (Nandy et al., 2001). Providing palliative
care could therefore be seen as a balancing act, wanting to provide care and
receive referrals because of the rewards of caring for palliative care patients, but
also being aware of the potential for such care to be emotionally draining and
difficult.

Palliative care is an exemplar of general care, particularly district nursing, placed in
a central and symbolic position within the case and workload (Goodman et al.,
2003). However Goodman et al. (2003) point out that there are many other
patients on the caseloads of district nurses whose chronic complex needs require
the same skills, but who are not seen in the same way as palliative care patients.
Palliative care is self-evidently important, and is linked to a medical and social
understanding of what constitutes important work. This could be crucially important
to referral behaviour, with professionals anxious to retain care of a group of
patients who could be argued to add status to their case and workloads, not by
virtue of the skill set required to provide care, but because of the significance given
by their own and other professionals to providing care to those who are dying.
7.7 Summary

This chapter explores how aspects of professionals’ own perceptions of their role, and the freedoms and constraints they had regarding their role, had an impact on the way they received and made referrals for palliative care patients.

Professionals’ conceptualisations of their role could have an impact on referral practices because of the discretionary nature of referrals within community palliative care. Referrals between services were never ‘automatic’, as even where there were referral protocols professionals could interpret them in different ways. This discretionary approach to referrals created the context within which individual and even idiosyncratic views about referrals could occur.

A core issue which could impact upon referral practices was a sense of self determination, and the exercise of independent clinical judgement. These elements of autonomy were protected, and promoted where fragile through ‘back door’ and ‘by default’ methods. Such approaches to practice were facilitated in community care by the relative invisibility of services, and virtual lack of direct supervision primary care professionals enjoyed. The referral criteria and guidelines which were developed by some services, but which were not mandatory, could be put to one side, with other more personal influences affecting referral behaviour.

Such influences included developing a sense of responsibility for or relationship with patients, which then appeared to promote patient ownership by professionals. This direct connection with patients appeared to give professionals a sense of power and control over whether they ‘kept patients to themselves’ and restricted referrals, or ‘shared’ patients and made referrals. These decisions appeared to be influenced by the perceived extra value of the referral to the professional to access additional expertise, buy time, control workload, or meet emotional needs. Throughout this chapter, there is a sense of the pre-eminence of the needs of the professional in triggering referrals. Whilst the initial referral prompt appeared to be the patient centred ‘reason for referral’ discussed in the previous chapter, this reason then appeared to be filtered by the professional to judge whether a referral was warranted for that particular patient, in that particular caring context, and to meet the particular requirements of the referring professional.
These behaviours beg questions about the effectiveness of local clinical governance. Clinical governance should ensure local delivery of high quality healthcare, safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish (Department of Health, 1999). It was not an issue raised in interviews, observed in meetings, or reflected in the documents collected. Whilst there are questions about what ‘best care’ in palliative care is, it appears that some of the practices discussed by professional respondents were unlikely to represent best quality care, and yet there seem to be no arrangements in place to identify such practices, nor less make improvements.

The issues which professional respondents chose to reveal in the interview settings regarding their conceptualisations of their role, such as a sense of self-management, issues of ownership of patients, and the desire to develop a relationship with patients were not reflected in the documents scrutinised or the referral meetings observed. This other data was more focused on the overt ‘reasons for referral’ discussed in chapter 6, rather than personal issues which appeared to have more of an impact on referral making and response to referrals. It is likely that referral policies may only have an effect on practice if they take due account of these more personal influences.

The next chapter explores how the way professionals interacted and worked together affected the way they made referrals.
Chapter eight

Working with other professionals in palliative care
8.1 Introduction

The impact of context, referral practices, and professionals’ perceptions of their own role on referrals and their management within community palliative care services are explored in the previous three chapters. In this chapter the impact on making and accepting referrals of professionals’ perceptions of others with whom they work is explored. Three main issues are examined: knowledge of other services, negotiating team roles and maintaining professional relationships, and judging other professionals. The data within this chapter are primarily drawn from interviews, but also from observational data of professionals working together in meeting and referral situations. Again, a cross-case analysis is presented, but where differences between the cases existed these are highlighted and discussed.

8.2 Knowing about other services

A key factor in referral decision making was professionals’ appraisal of how much they understood about the work of fellow professionals and services. Three interrelated issues were apparent from the data: descriptions of poor understanding of how other professionals worked; acknowledging the variability in how different professionals approached their work in palliative care; and a tailoring of referrals made to fit with what professionals knew specifically about the work of colleagues.

It was common for respondents to indicate in the interviews that they knew little about the work of others, including those from their own professions. This resonates with the data presented in chapter 6 about the lack of knowledge patients had about services.

‘You don’t actually get to see what other people do, so I don’t know what other team leaders do. I don’t know what other district nurses in other teams do. I feel we are isolated which I don’t necessarily think is a good idea, because there could be things I could be doing better, which I don’t know about.’ (A/DN5)

‘I don’t know what other people’s qualifications are throughout the board or the trust, there could be vast amounts of people out there with vast amounts of palliative care education, but I would say it’s probably a minority rather than a majority of people.’ (C/DN2)
‘I haven’t a clue where it [case study B cancer pathway service, established 3 years previously] fits in, they seem to be very good at, I never refer people, they seem to be regularly referring people elsewhere but never doing anything, I don’t know what they do, I really don’t know what they do and how they work.’ (B/GP1)

‘[describing the role of the GP in palliative care] Well, I suppose they, I don’t know what to say, I don’t know really, I mean they’re the ones who refer in the first place to make the diagnosis, they’re the ones who chase up the medical side I think, I suppose they would be …’ (A/DN4)

This lack of understanding of others’ roles appeared across all the case study sites, and related to those from a respondent’s own profession, those with whom respondents worked regularly, and new and developing services. It seemed hard for professionals to keep up to date with current developments. This was particularly highlighted in case study A, where for much of the study period there were few specialist staff in post due to retirements, resignations and long term illness. This general practitioner for example, appeared unaware of the current staffing issues within the team:

‘I’m sure there was some sickness recently, somebody was off, and I think there’s two, and I don’t know if they’re full-time, but there certainly doesn’t seem to be enough Macmillan.’ (A/GP1) [no nurses in post at time of interviews for several months]

An issue was the fact that for many respondents, work in the community was an unseen service, conducted without observation in patients’ homes, and so it was difficult to demonstrate visibly to others what they did:

‘It’s like district nursing, an invisible service, unless you’ve actually met a district nurse, or had a district nurse service, or had district nurse intervention, nobody knows actually what we do, and it’s like that with Macmillan nurses, unless you actually come across a Macmillan nurse people don’t know.’ (B/DN1)

This lack of knowledge about the roles of others is also apparent in the work of other researchers. The ‘invisibility’ of the district nursing service in particular is noted, both to those with whom they work as well as those outside the service (Griffiths and Luker, 1994; Griffiths, 1996; Goodman et al., 2003). In addition, lack of knowledge and different perceptions about people’s roles is reported with regard to Macmillan nurses (Clark et al., 2002), between general practitioners, district nurses and Macmillan nurses (Burt et al., 2005), and between district
nurses and social workers (Bliss, 1998). A few studies reviewed in section 2.3.5.1 identified that not knowing about services may impact on referrals (Bestall et al., 2004; Bradley et al., 2002). Such lack of knowledge about services in this study would be likely to have an impact on referral, with people unlikely to refer without knowledge about the role of the service.

There were examples in this research of respondents being able to give an account of the work of others which appeared to agree with the accounts professionals gave of their own work. This general practitioner spoke about the work of district nurses in a way which tallied with the descriptions nurses themselves gave:

‘They work as an access point to nursing care; they act as an access and referral point to other agencies like Marie Curie. They work on getting things, so they can get beds and stuff like that for us. But they tend to be the people who go in and administer things like syringe drivers, and stuff like that, where there is quite intense nursing, where somebody, they also tend to be the people who monitor symptoms for us towards the end stage.’ (B/GP1)

Whilst this impression of district nursing did not convey the entirety of the role district nurses described, particularly their desire to provide a more supportive role not necessarily focussed on physical symptoms, it appeared sufficiently accurate to facilitate referrals which were likely to be appropriate.

This understanding of the role of others appeared critical, as hypothesised, to the decision to refer to others, clearly articulated by this specialist nurse:

‘I think it’s all about learning each other’s roles, because if you don’t have a clear understanding you tend not to refer, because you don’t understand what they’re doing, so what are they going to do that I can’t do, um, so I think there’s still a lot of that, I think there’s a lot of work to do in palliative care.’ (A/SN2)

The influence of the understanding of others’ roles in affecting referral practices is discussed by Bliss et al. (2000), and found in the work of Burt et al. (2005).

However, despite the thread through many interviews that it was difficult to appreciate and understand the work of others, there was also a counterbalancing theme – that of understanding the variability in the way different professionals
understood and performed their roles. Such variability appears common, with reports of district nurses being variable in the extent to which they involved patients in decision making (Millard et al., 2006), of palliative homecare teams being variable in the way they were set up and operated (Boyd, 1992), and of Macmillan nurses having variability in location and context of services, activity levels, management patterns, work organisation and content, links with other colleagues and resource use (Clark et al., 2002).

Whilst these themes of ‘knowing about other services’ and ‘knowing about variability’ appeared at odds with one another, it was not uncommon for a respondent both to identify issues with understanding others’ roles, and also to acknowledge that they were aware of variability – usually because they had experienced or observed the diverse responses to referrals of different practitioners. Respondents acknowledged the differences within their own professions, as much as differences between professionals with whom they worked:

‘That’s a bad thing about district nurses, we all, we all do it slightly differently, and we will, we will see [palliative care] patients what other teams won’t see … although we all work together at weekends, but even so there’s no, there’s nobody checking up, you could do as much or as little as you wanted really, nobody knows what people are doing at the moment, so I’m saying, I go and do observation visits, you might find another district nursing team won’t.’ (A/DN4)

‘… so we visit our [palliative care] patients quite regularly. Now other district nurses that you may meet may not do that.’ (B/DN1)

‘There are some GPs who cannot, will not or prefer not to get involved with that sort of care [palliative care].’ (A/GP 2)

‘What we do here is more than a lot of GPs do, but I think it’s what GPs should do … our district nurses do more than other district nursing teams, and it’s about, I think it’s about interest and competence, and they’re interested and competent, and, and feels quite supported, so it seems to work reasonably well, but I don’t think that happens elsewhere. Yeah, and I think I’ll leave it at that.’ (B/GP1)

‘I: Do you think the cancer plan has made a difference to the way that palliative care is provided within the PCT? C/DN4: Probably not within the PCT. No, because, I mean, it depends on individual practices, individual teams of staff, GPs, district nursing teams, how the palliative care services is provided really. Because district nurses, well,
different professionals interpret things differently don’t they, they all work differently.’

There appeared to be an acceptance of this variability in others’ working patterns, in much the same way that variations in an individual’s interest and expertise in palliative care were accepted, as discussed in section 7.4. They were quick to judge the actions of others, presented in section 8.4, but appeared to compensate for the perceived deficits of others through their own work, rather than challenge others’ practice. This acceptance of the variability of the approaches and standards of others is also found in the research of Speed and Luker (2004). They found that care was left to the discretion of the individual district nurse, with this culture supported by the fact that nurses worked in isolation from each other. Nurses in their study reported accepting the judgements of other district nurses because they did not have the same awareness of the patient or their individual circumstances. Earlier work confirms this tendency, with district nurses found to use unspoken rules to support colleagues and avoid conflict (Griffiths and Luker, 1994).

However, there were some indications of ways of ensuring a consistent approach, generally through informal discussion of working practices, rather than formal benchmarking processes:

‘I think we probably work similarly, because we do have meetings, Macmillan meetings, where we discuss clinical issues … I think we all work in a core way the same because we have always worked as a team and when I came into post my colleagues sort of gave me an induction on how to work.’ (C/SN2)

Respondents were also very aware not only of the different approaches of those within their own professional group, but of those from other groupings with whom they worked. It was common for comparisons to be made regarding the approaches of different generalist professionals such as general practices and district nursing teams. This was probably because individuals came into contact with many different teams and practices, and so felt able to make a well-founded comparison. It was rare for such variability to be identified in specialist teams, generally because people worked exclusively with one individual, hospice or service, and had no experience outside this to compare with. The exception, as discussed in chapter 5, were the comments made about the difficulties within the Macmillan team in case study A. Comments about general practitioners were
made individually, but it was also common for discussions to focus around the different approach of practices, rather than the individuals within those practices:

‘There’s four [GP] practices here, so they work very, very differently, all four practices.’ (C/DN3)

‘There’s some [general] practices that refer on, and some that don’t refer and some practitioners that refer on, and some practitioners don’t, never refer, and the reasons for that I’m not 100% sure of really.’ (A/SN4)

Again, comments about district nurses tended to refer to teams, although here they were referring to a team headed generally by a single district nurse, and shaped by their personal viewpoint, in contrast to the approach of a general practice, which may have many general practitioners within it:

‘I’ve realised that district nursing teams don’t always work in the same way, and that has been a bit of a surprise to me.’ (B/SN2)

‘I don’t think there is any clear policy to say well, you should do this, and you should do that, and because it’s so variable and it will vary between two district nursing teams within the same area.’ (B/AH1)

The critical impact of such variability, and awareness of variability amongst referring staff, was that it appeared to have an important impact on the way that people made and responded to referrals. For example, generalists recognised that specialist nurses could respond differently to different teams, depending on the expertise of the team:

‘I think it [input of Macmillan nurses] differs with whichever team they are working with, I’m sure that if you have got a practice that is quite interested in palliative care, and maybe people who have had experience in working in hospices and things, then their input is going to be different from a practice that maybe is not so geared up and motivated.’ (C/GP5)

This variable response of specialists to referrals, reflecting the interest, ability, and predicted response of the person from whom they received the referral was clearly stated by specialists:

‘If you know that you have got other professionals who perhaps don’t provide the same standard of care as other professionals do, or other people that you work with, then that might give me cause for concern as to whether that patient (a) has been assessed properly, or (b) has had their needs met. In which case I might prioritise that over and above somebody that I know has got a good district nurse if you like going in. In fact I would prioritise that
above, if I had two referrals, one with a good district nurse that I knew and trusted, and I knew she could cope, and one that was crap basically, then I know which one I would go to first.’ (C/SN1)

‘I sometimes think that the definition of someone needing specialist palliative care is, is more based on the skills and enthusiasm of their GP and district nurses, or, and/or the hospital ward team, whether being cared for is more about that, than the actual needs of patients, because some patients have very simple problems, will need to be referred because their professional carers are out of their depth, and others with quite advanced disease and difficult problems will be managed very nicely by the teams who are managing them.’ (B/SD1)

Specialist palliative care nurses report the fact that they cannot trust the performance of some other health care professionals as a source of stress, so they take on extra work, or retain responsibility for tasks (Newton and Waters, 2001). This again reflects a differential response to referrals depending on an appraisal of the referrer, rather than the patient’s needs.

It seems from the data in this study that there were many circumstances where it was not necessarily an assessment of an absolute level of patient need which was the trigger for referral, or which affected a response to referral. Rather there seemed to be a complex interplay between the referring professional’s appraisal of the situation, and the assessment of the professional receiving the referral. Therefore a referral may only be made by certain professionals under certain circumstances, for example where expertise, time or interest was lacking. This referral was then dealt with in a particular way by the professional receiving the referral on the basis of their assessment of the professional making the referral as much as the information about the patient contained in the referral.

The way this process was achieved was often through past knowledge of teamwork, and a sense of a negotiated etiquette of referral. This is explored in more detail in the next section.

8.3 Negotiating team roles

Concepts of teamwork, professional relationships and team leadership are discussed in this section.
8.3.1 Concepts of teamwork

The concept of ‘team’ appeared critical to the way many respondents viewed themselves and their work. This is perhaps unsurprising given the prominence placed on teamwork, partnership and collaboration in current health and palliative care policy documents. An emphasis on partnership as a key component of service improvement in palliative care is not new (National Council for Hospice and Specialist Palliative Care Services and National Association for Health Authorities and Trusts, 1998). However, despite little evidence that team working in primary care has been successfully adopted from previous policies (Poulton and West, 1993), the drive towards partnership and teamwork as a mandated element of successful palliative care is increasing.

An inter or multidisciplinary team approach to coordinating palliative care is routinely accepted now as good practice through its promotion in the World Health Organisation’s definition of palliative care (Sepúlveda et al., 2002) and European documents such as the Council of Europe’s recommendations (Council of Europe, 2003) on the organisation of palliative care. In England, guidance on how palliative and supportive care services should be both provided (NICE, 2004), and funded (Department of Health, 2003b) require partnerships to be in place to successfully deliver services and provide local funding plans. The new supportive and palliative care guidance places particular emphasis on partnership working as a vehicle for change and improvement at the level of the cancer network, service provider and patient (NICE, 2004). Given this recent and past emphasis on the importance of team working within palliative care, and the normative sense that collaboration is a positive thing (Hudson et al., 1999), it is perhaps unsurprising that respondents discussed its importance.

Many respondents indicated that they delivered the best possible palliative care to patients when they worked as part of a well functioning team with the appropriate expertise:

‘I think the best care for patients is that which is palliative partnership, and as they’re at home for the majority of their lives with their illness, that’s where their care has to be provided, but it has to be skilled and experienced and appropriate care.’ (B/SD1)
‘We have all been involved with this lady, she’s a youngish lady, the Macmillan nurses are involved too, other district nurses, she comes here to the hospice, she has complementary therapy, she comes to see the palliative care consultant, this is, although it’s a young lady and it’s really a very, very sad situation, this is one of the nice situations where we are all working together for the benefit of that patient, you know, nobody is sort of pulling any hierarchy, we are all working together, all getting on, all communicating, and I feel that, that lady is getting the best care that she could possibly have.’

(B/SN2)

In this situation described above, referrals to many different services appeared to have been made to facilitate the number of different professionals working with the patient, which then led to a sense of team arising from that situation. However, despite these reports by professionals of the benefits of teamwork, there were indications that such positive teamwork was not always experienced and delivered to patients. Even in the two data extracts above, there were indications of conflicts experienced with teamwork. In the first, B/SD1 acknowledged that partnership care has to be well-provided, hinting that this was not necessarily always the case. In the second extract, the implication was that sometimes there were hierarchical, communication and relationship issues between potential team members. The rhetoric of teamwork may not always be transformed to reality.

Research in other fields, such as mental health found that whilst people can provide clear accounts of the benefits of working closely with other professionals, observations of practice reveal examples of tribal behaviour (Stark et al., 2002). This relates to the concept of collective efficacy, the idea that it is necessary for group members to believe that the combined efforts of the group are not only necessary to obtain a shared goal, but that each member is capable of and willing to do its share of the work (Johnson et al., 2003). There are many barriers to collective efficacy, and it may be that the communication, hierarchical and expertise issues raised here may militate against effective teamwork.

It was also apparent that team meant different things to different people. For example, although C/GP1 discussed close liaison with district nursing colleagues based in the same building, team appeared to mean the practice based staff:

‘C/GP1: We like to think that we liaise very closely with our community nurse, and we meet regularly ....
I: And so when you say we work as quite a close team, who specifically are you referring to within that team?
C/GP1: Well, in the practice, because it’s only a small practice, myself and my partner exchange information regularly, but also our practice nurse is usually well aware of the [palliative care] situation … but even our reception staff and our secretary will be aware.’

Again A/SN1 felt that the relationships with those who were employed on the same basis, essentially working for the general practitioners, affected her sense of team and team relationships:

‘I work very closely with a wide spectrum of people, the main people here are the other specialist nurses in the practice, so work closely with them as an integrated practice nurse team, the district nurse team are PCT employed, whereas we’re all practice employed, um yeah, very close relationship with the GPs.’ (A/SN1)

Similar comments were also received from B/SN3, involved in an outreach service in case study B, which struggled to create a sense of team with other professionals working in the same area:

‘They [specialist palliative care professionals] interact with us, and they are part of our team, but they’re not based with us, they’re actually still based in, in the hospice teams, because obviously they need their support, and that’s been a difficulty really, how that’s, when we’ve wiped out, … we’re part of a PCT, and obviously the palliative care team is part of the hospital, and the hospice, I feel really one of the problems for us is that we’re not specifically attached to palliative care.’ (B/SN3)

Team, to most respondents, appeared to be the people who most closely shared their physical space, who shared the same employer, and who often shared the same professional background. Therefore team, to most of the specialist and district nurses appeared to mean the team of (usually) nurses with whom they shared office space. To the general practitioners team often meant the practice based and employed team. With such teams, there appeared to be a sense that patients passed between team members without formal referral. For example, different members of the district nursing team would be involved in caring for a patient, or a patient could see different general practitioners. So, for example, A/SN1 here describes the way she shares electronic notes with the General Practitioners with whom she is based, and has a sense of team with, so that a formal ‘referral’ doesn’t have to be made between herself and the general practitioners:
‘So that it makes their [GP] consultations a bit easier, because the paperwork is all there, they know that they’ve got all the reports ready to hand, you know ... so when they see somebody they’re not going to faff around, and not know what they’re up to, and they’re informed you see, they know now when that person crosses the door, exactly what the last 10 weeks has meant to them.’ (A/SN1)

Team, however, within palliative care in the policy documents referred to earlier in this section, appeared to refer to a wider multi-disciplinary team who come together specifically to care for a patient or group of patients. This sense of team would require formal referrals between professionals for its formation. The concept of team in the policy documents was certainly recognised by respondents:

‘The district nurses have a very good relationship with the patients, irrespective of which doctor has been looking after them, and we do, um, you know we do need to work as a team.’ (A/GP3)

‘And they’re all based here [specialist palliative care professionals at the hospice], so although we’re all employed by different organisations, in practice we try and work as a team.’ (B/SD1)

However, even in this situation where a base was shared together, there were indications that team work was difficult to achieve:

‘I have always felt that the Macmillan nurses, obviously from only from my own perspective, have been very separate from us, and that there is great potential to work really, really well together. Although they are based here [hospice], I mean historically they do not feel to me quite as integrated into the day-to-day running of the patients care.’ (B/AH1)

In the situation described above, for the Macmillan nurses to work in a team for a particular patient appeared to require a formal referral to be made, rather than the informal information sharing described earlier by A/SN1, even though they were based with those who may be referring. However, generally the structures, such as physical proximity, or regular meetings, which support the way professionals provide care appeared important to the perception of team effectiveness. For example, it has been shown that a significant proportion of general practitioners become dissatisfied with the level of cooperation with a palliative home care team after a month because the format of cooperation via a home care conference is inconvenient to them (Goldschmidt et al., 2005).
Patients rarely spoke about teams, talking more about individual professionals and the way they cared for them. This probably reflected the reality of care at home for them, experienced as a succession of visits from professionals to the home, or by themselves to facilities such as the hospice. However, when they did talk about team, they appeared to conceive of a series of teams caring for them, who could communicate and collaborate with each other, or else fulfil individual roles which did not overlap, as in this extract:

‘I’m not sure about any interaction between the GP practice and the palliative medicine team, but I think, I would imagine there is more likely contact, I think they interact well, I don’t think there is anybody overall co-ordinating that contact necessarily, there may be I don’t know. I would imagine there is contact between palliative care and district nurse, I imagine there is contact between them and [name of oncology unit] but I don’t think there is contact between the palliative medicine team and my GP practice. I don’t get the impression of anybody overall, I get more an impression of them meshing, I think they do mesh like cogs I don’t think there is anything I can think of that they don’t cover between them.’ (B/P5)

These issues of teamwork and the concept of team both in an ideal and a practical sense appear to be bound up with a confused understanding of what team actually means. First, there is confusion between team and teamwork. Team can be conceived as a structural entity, whilst teamwork is a way of collaborative working (McCallin, 2001). It is likely in the extracts above that sometimes people were referring to a structural team, founded around perhaps a shared working base. In other extracts they appeared to refer to teamwork, a notion of working collaboratively across structures and disciplines. Second, there appear to be different types of team. Different types of team collaborate on a continuum of professional autonomy, from what has been described as ‘autonomous parallel practice’ of people working collaboratively but independently, to ‘integrated teams’ which are more autonomous as a whole (D’Amour et al., 2005).

In the palliative care contexts seen in the three case study sites explored here, it appeared that there were examples of different forms of teams which individuals belonged to, as well as examples of teamwork. It may be that terminology needs to be used in a more careful way to avoid confusion about the ways of working to which people are referring. These different concepts of team and teamwork appeared to demand different ways of referring. In a ‘team’ professionals often shared patient care, with little need for formal referral. However, it is noted that
palliative care professionals often work not in formal teams, but rather as a ‘web of loosely connected services and individuals’ (Corner, 2003). Such a ‘web’ of services is formed and re-formed constantly for patients, based on referrals to and discharges from particular services and/or individual professionals. It may be therefore that what is affecting referrals in palliative care is not ‘teams’ but ‘teamwork’. The other term used to describe this form of organisation is network, and Bardach’s (1994) description of a provider network seems apt: ‘A single ‘client’ may receive service from one or more agencies in a ‘network of providers’ linked by expectations of giving or receiving referrals, joint ventures, professional norms and the like’. He defines network as ‘a set of self-organising working relationships among actors such that any relationship has the potential both to elicit action and to communicate information in an efficient manner’ (Bardach 1994 p4). However the positive connotations of eliciting action and communicating information are tempered by his recognition that networks can also be places of strain and unpleasantness, beginning warily, and possibly affected by individuals attending to their own needs as much as those of clients. The data from this study resonates with this recognition within a theory of networks that the relationships between actors are important. The ways individuals negotiate working patterns, and therefore teamwork or network relationships, appeared fundamentally important to referral and are now considered further.

8.3.2 Negotiating and building relationships between professionals

Formal or informal referrals between health care professionals appeared key to the formation of ‘webs’ or networks of professionals working together in community palliative care services. Generalists such as district nurses relied on referrals to their services principally from general practitioners and hospital services. Specialist palliative care services relied on referrals from the generalists caring for such patients. The provision of specialist palliative care in particular was ‘by invitation only’ and specialists were mindful of their status as supplementary health care professionals, whose presence was negotiated by the generalists. This could make them very cautious about the way they worked so that they maintained good relationships with generalists to facilitate future work and referrals. Many of the comments relating to this issue came from the doctors interviewed:
‘I suppose it’s a bit more challenging as a palliative medicine doctor, because we don’t just need to decide what to do, we need to convince somebody else to do it … because there’s no point me seeing them, offering advice if they’re [generalist] not going to follow it.’ (C/SD1)

This caution appeared well founded, as there were a number of generalists interviewed who were sceptical about some of the benefits of specialist palliative care, and nervous about what the involvement of specialist palliative care services could mean for their own involvement with patients. Those working in specialist palliative care were aware of these concerns of generalists with whom they worked:

‘Some of my more enthusiastic colleagues in dealing with patients at this stage in their life would perhaps fear or think about not wanting us to take over, and, but I’ve, because I know who those GPs are, I think we would tend to, I hope we could have a negotiated sort of shared care approach to their patients care.’ (B/SD1)

There was a very strong sense in many of the interviews that referrals to specialist palliative care services were optional for patients, not automatic. Such referrals had to be carefully negotiated, to recognise that the role of the specialist was essentially advisory and additional to care.

For nursing staff, such negotiations, and experience of prior difficulties led to the development of the negotiated etiquettes of care with regard to nurse to nurse referrals, and the timing of such referrals, discussed in chapter 6. It is worthwhile re-emphasising such negotiated orders here, as they not only facilitated appropriate referrals, they also reinforced the negotiated relationship between the professionals concerned:

‘The district nurse is more like the gatekeeper, she does the general, everyday care of the patient and then identifies when specialist care is needed… we make the decision once the district nurse has done the assessment, because they are the main carers ...’ (C/SN3)

‘ … Having checked it [referral] out with the district nurses first, I think that avoids the potential for conflict. I could see there would be potential for conflict if for example the GP referred straight to us, and we just decided well, we needed to go out and make an assessment.’ (B/SN1)
‘But the Macmillan nurses are very good, and if they have had somebody referred to them that we don’t know about they would let us know before they would visit.’ (B/DN3)

These extracts appear to emphasise the importance of such negotiations over referrals, not just with reference to the immediate referral being made, but also to maintaining an ongoing trust in their professional relationship over time by avoiding conflict. It also appears to again sideline the patient’s needs or expectation of referral, and prioritise the maintenance of a relationship between professionals. A study by Cowley (2002) highlighted the importance of trust, identifying that contact between professionals over time was required to build up the trusting relationship needed to facilitate joint working.

This sense of needing to tread cautiously with the provision of specialist care to maintain good relationships with generalists created a real tension for specialist palliative care professions, because of their awareness of the great variability in knowledge and skills which the generalists they worked with had to offer to patients, and the attractiveness of specialist services to some patients:

‘I think the difference from a general point of view is that general palliative care really should be an integral part of every health care professionals’ domain, that they should have the skills and ability to be able to recognise basic symptom control, to deal with basic symptoms, to have open and honest communication with patients, to be able to sign post them in the direction of services and know the limitations. Because I think there are people out there who don’t know the limitations either, and will say I actually don’t need to refer through to Macmillan nurses because I can do it. OK maybe some people could do it, but the depth and the level of knowledge would be questionable and I think that people have to know their own limitations.’ (A/SN3)

‘How much if we referred someone do we send the troops in, do we take, do we haul them out, or do we just have a watchful presence, offer advice from a distance, support those who are providing the care? That’s an ideal scenario, but sometimes it is difficult because once a patient is aware of you, and the services you represent, they become attracted to that.’ (B/SD1)

Those providing specialist services appeared to find themselves in a very difficult position, whereby they needed to maintain an excellent working relationship with generalists to facilitate referrals and patient care, but were also concurrently aware that some professionals with whom they worked did not provide care of a standard which they felt appropriate. This resonates with concepts of team cohesion, which is based on social cohesion (the strength of the interpersonal ties between
members) and task cohesion (the value placed on task competence) (Davison and Sloan, 2003). It appeared that individuals in this study may have been prioritising the social cohesion of the team over the team task of caring for patients.

Professionals recognised that the relationships they had, and the perceptions which they had of each other influenced the way they worked together and the referrals they made. This meant that they appreciated that efforts needed to be made to build relationships which facilitated their own working practices, and the social cohesion of the ‘team’:

‘The key things are the good relationships between all three people [district nurse, general practitioner and Macmillan nurse] and knowing what people do, and what people do well, and having that trust and understanding of each other’s roles really, and their competencies.’ (C/KI3)

‘Having professional respect, and sometimes they might do something, and you think, “Oh God, I can’t believe they’ve been in there and said that to a patient”, but that’s what that service is about, and you have to kind of work best together.’ (B/DN1)

There was an appreciation that relationships needed time to develop, and that the relationships between professionals had to endure beyond the care of an individual patient. Thus, primacy was placed on routines which facilitated an ongoing working relationship that met professionals’ needs. These appeared to supersede the patients’ immediate needs. Again, there is an emphasis on social cohesion of the team above the task cohesion of caring for that individual patient:

‘The relationships with GPs is very much feel your way, and find your feet, that way you see just how far you can go and how far you can’t go. Because, I think the problem is, once you have blown it with a GP, you’ve blown it, and that is it, it’s not easy to get back in with them.’ (B/SN2)

Each professional could be judged on the basis of each current and past interaction, and they were mindful that the successful referral and care of future patients could depend on their negotiation of a continued successful relationship with others involved in the care of current patients. This could mean that the care of current patients was compromised in order to maintain and enhance a professional relationship which would facilitate the referral of and care of patients in the future. It is recognised that even autonomous professionals are
interdependent on each other, and the risks of ‘rocking the boat’ and unsettling a relationship are often perceived as too high (Goodman, 2001).

However, the maintenance of this careful relationship with doctors described by nurses does not appear reciprocated in the data from doctors. Whilst doctors often appreciated the working relationships they had with nurses, and valued their skills and input, the respondents did not describe having to negotiate care and relationships in the way that nurses did. This may be because of the difference in power the individual professionals had, and the de-facto leadership role which doctors tended to assume, discussed in the next section. There are indications that general practitioners make such estimations in their referrals to fellow medical professionals, with the anticipated ‘peer review’ of the general practitioners professionalism about referral decisions to admit someone as an emergency found to influence referral practices (Dempsey and Bekker, 2002). The relative lack of discussion of doctor to doctor referrals in this research gave few opportunities to corroborate such findings.

Thus it appeared that the focus of much professional interaction was the maintenance of a sufficient relationship to allow them to care for current patients without compromising the care of future patients. This influenced the way they made and received the referrals which formed the basis of these interactions.

8.3.3 Team leadership and the key worker role

Issues of patient ‘ownership’ between formal and informal teams or ‘webs’ of professionals were discussed by respondents in terms of key worker concepts. It was common in the interviews for respondents to discuss ideas about key workers, although there was neither formal identification of the concept, nor means of identifying a recognised key worker for patients in any of the local documentation or policies analysed. The concept therefore appeared to be informally defined, and operationalised according to the beliefs individuals had about their own roles and the roles of those with whom they worked.
Most commonly, the district nurse was identified as a potential or actual key worker. Every single district nurse interviewed identified themselves as the actual or ideal key worker for the patients with whom they worked:

‘I: Is there one person who takes responsibility for coordinating all the care that’s happening with these palliative care patients?
A/DN3: it’s usually the district nurse who, um, because we’re the ones who have the most input.’

‘We always say the district nurse is a care coordinator because of the contact, the initial contact, and also the contact with the GP, and like we sit in the middle, and everybody is referred out around us, so we always try to promote that those services feed back to us so that we know what’s happening.’ (B/DN1)

‘I would coordinate it because I would be the one doing the initial assessment, and would then, it’s a bit of a knock on effect but it’s just the communication, that I tend to lead on that, and because I would probably refer to the Macmillan nurse … it’s always fed back to me, she always communicates with me … she always comes back to me as the main person who was dealing with that patient.’ (C/DN5)

All the district nurses perceived themselves as central to palliative care. They identified themselves in this position generally because they acted as a communication conduit regarding information about the patient, made many of the referrals, and also because of the degree of input over a period of time which they had with patients, and the relationships they developed as a result of this. This identification of the district nurse as key worker was also shared with a significant number of other professionals across each of the case study sites, again citing a rationale based on frequency of contact, length of relationship, and referral and liaison role:

‘I don’t know whether I see her as the stem of an umbrella … like we’re saying is that we are like sometimes the first point of contact, as a district nurse, I would see them, yeah, basically as the main stem, feeding out and receiving that information about that patient and making sure that you’re using all spokes of the umbrella.’ (A/SN2)

‘The district nurse should be the, sort of the key person, should be involved as a main nurse attached to the GP as early as possible at diagnosis, and then um, you know, can monitor the patient’s care throughout the journey really, while they’re at home and liaise with the specialists and other people in order to make sure that they’re getting the right information and the right support.’ (B/SN3)
'I feel that they’re [district nurses], the key people really, because they have a more general kind of role, an overview sort of role that they deal with all sorts of the day to day care, symptoms, treatments, drugs, all that kind of thing … as well as that kind of role with the family that they become quite a key person because they are visiting more regularly that they can pick up on all sorts of family stuff.' (C/AH1)

Other research found that district nurses invariably identify themselves as key workers (Mcilfatrick and Curran, 2000; Austin et al., 2000; Burt et al., 2005; Dunne et al., 2005). However the concept of the district nurse acting in this key worker role, although dominant, was not one held unanimously. General practitioners could be more equivocal, often promulgating their own, ‘unrecognised’, key worker role:

‘I would say that the GP would coordinate it, but I do stress they’re not, we’re just part of the team, but I think that is, that is part of our, that is our role, I think we’ve got to be very clear on that, and so our responsibility and duty to do that.’ (C/GP6)

‘People seem to forget that we are still key workers, probably sometimes when you’re referred to palliative care they do seem, sometimes, to take over. And they do sometimes forget that we are key, key with everything really, um, and we have we know the patients, we know the families, we know them very well, we have a huge amount of background information.’ (B/GP4)

Others’ research with general practitioners also recognises that they value palliative care, seeing it as a rewarding part of their role where they could act as team coordinators (Field, 1998; Mitchell, 2002; Desmedt and Michel, 2002). However, recent work in this field does identify a range of general practitioner opinions as to whether they have responsibility for coordinating care (Groot et al., 2005a). Burt et al. (2006) in a postal survey of general practitioners found that 72% felt palliative care was a central part of their role, and only 27% wanted to hand over care to specialists.

Other respondents in this study did not identify the general practitioner as a key worker in palliative care provision except as a team member alongside the district nurse:

‘I mean the GP, often having had a relationship with either the patient or the family over a number of years, is often the person who sort of knows them best, and so I think he or she is the key person … but I see the GP and the
district nurse being the key workers, and as a specialist service, very much being complementary to that.’ (B/SN1)

It was less common for members of the specialist palliative care team to be identified as key workers, although again, some respondents did identify them in this role:

‘The community Macmillan nurse is a coordinator of palliative care; they’re GPs in palliative care. Is, how I would see it, so they, they can advise on symptom relief, advise on drugs, they can advise patients on access to services, what services are available, where the services are available, how to access them. They can help patients with accessing social work, and appropriate benefits, they can, they’re good information gatherers, they’ll go and find things out and chase things, up, that’s what a GP does, or should do. I think, that’s probably why I see their role and my role as being very similar, I mean I did it for everybody, and they do it for just people with palliative care needs.’ (B/GP1)

‘I: Is there any one person who had a responsibility for coordinating their care that they receive?
A/GP1: I would think for us, that’s A/SN1. She sort of keeps check on everybody that’s involved to make sure that things are happening that are supposed to be happening and chases it up, so I would always ask A/SN1.’

Specialist palliative care providers tended to identify themselves in a key worker role only because of the perceived failure of generalists. They emphasised the generalists as key workers, again maintaining a negotiated etiquette of care, but were aware that they had to fulfil this role sometimes if the generalists were not willing or able to do this:

‘Very often things are lacking or people are not joining together, and I feel sometimes almost like we become a key worker if you like in somebody’s care, and you are the one constant because district nurses change and go off and do whatever, the GP if it’s a group practice will change, you know, they don’t always get the same GP and sometimes it’s good to have one contact person who will take the time to contact everybody else, and let them know they are involved and gather information and sort out appointments, or liaise with people.’ (C/SN1)

‘The reality though is that, as I say, district nurses are very stretched and yes they may know of somebody, but actually being involved with their care is very, is almost impossible to ask of them, so they say this [key worker role] is what they should be doing, but in reality maybe are unable to do so.’ (B/SD1)
There were also respondents who felt that it was incorrect to assign a key worker role to someone purely on the basis of their professional background, but that the person who fulfilled that role for a patient should vary, depending both on the choices that patients made, and the extent of involvement of different professionals with a particular individual patient:

‘People who’ve had, I don’t know, nursing needs, so frailty needs, tend to use one of the district nurses, so it tends to be [name of district nurse]. People who’ve had symptom needs, it tends to be us, so and you know it depends on the patient. So all of us can be leads, so it depends really on the patient on their needs, it tends to happen, there’s no system … somebody tends to evolve. But what I think we need to do is have that lead person identified maybe a bit earlier for people.’ (B/GP1)

Again, this view is also recognised in the research of others, with acknowledgement that there wasn’t a single person designated to take overall responsibility for care in some studies (Street and Blackford, 2001; Dunne et al., 2005). Even with the acknowledgement of this possible variance in key worker, there was also a strong feeling that generalists in primary care should have a key role to play:

‘The thing about primary care is that it does have that enduring connection with the patient over many years, so however the key worker is cut, whether it’s a specialist palliative care person, whether it’s a clinical nurse specialist, whether it’s anyone at any particular, when you pass the key worker on, well all of that can happen whenever, but there’s still this enduring connection with primary care, so you still need a lead within primary care.’ (A/GP3)

Thus, informally, many different people identified themselves as key workers and there was no indication when caring for a specific patient that the key worker was ever formally identified. Examination of patients’ case notes never revealed formal or informal identification of a key worker. Patients did not refer to the concept but tended to develop a ‘key worker’ type relationship with the professional who most frequently visited. It may be that, confusingly, several people perceived themselves in this role when caring for a patient. This may affect referral practices, as most respondents identified the key worker as the person who should have an overall responsibility for referral, liaison and communication. Without formal identification of a key worker, then multiple unnecessary referrals could be made, or needed referrals omitted.
A further issue in the debate about the key worker concept was its interrelationship with team leadership. General practitioners in particular were likely to highlight their leadership role irrespective of who would be the patient’s key worker:

‘I’ve always thought the district nurse is probably the key worker in looking after the palliative care. I think in good practices the GP obviously plays quite a good leadership role in actually helping to kind of bring people together and discuss and facilitate discussion, and tease out management strategies and things. But I think the district nurse is far more knowledgeable than the average GP.’ (C/GP2)

‘I think certainly where patients might have a sort of dominant personality, or there are quite clear issues, for example in pain relief or physical symptoms, then I would certainly look to myself or my partner as taking the lead there, and I think certainly from our nursing colleagues that they often want that, but on odd occasions, they do want somebody to say I am responsible.’ (C/GP1)

This assumption of a leadership role by medical staff was clearly seen in the team meetings observed. Each meeting observed was either formally or informally chaired by a doctor – either the general practitioner in the primary care meetings, or the specialist doctor in the hospice. It appeared to be the medical staff setting the agenda and leading and steering the meetings, with the nurse members fulfilling a subservient, quiet, role in the meeting situation. Most patients discussed in these meetings were identified by the medical staff. The nurses present, whilst often participating in the discussions of patient care, appeared to do so in a less comprehensive way than would be suggested from the data presented by them in an interview situation. Professional orientation appeared to be important here, not gender, as this was observed in meetings where the doctors and district nurses were all female, and where the doctors and nurses were all male:

**Field notes from observation of palliative care meeting, Case study C.**

I attended the regular (every 2 months) palliative care meeting at the surgery of C/GP5. The meeting was obviously organised by, and dominated by employees of the general practice. It was attended by 3 GPs, 1 GP trainee, and 2 receptionists. Apologies received from the community Macmillan nurse who was on a training course. The district nurse arrived late, having been telephoned at the start of the meeting as he had forgotten about it. The meeting was dominated by the GPs, who took the lead in deciding which patients to discuss, based on a practice generated cancer register. The district nurse, once he arrived, appeared to know most of the patients discussed, but only participated to volunteer information when asked, not of his own volition.
Field notes from observation of palliative care meeting, Case study C.

I attended the palliative care meeting at the surgery of C/GP1. This took place approximately every 2 – 3 weeks. It was attended by 2 GPs and 1 district nurse. The Macmillan nurse was an infrequent attender. The ‘list’ of patients to be discussed was prepared in advance by the practice secretarial staff, but who didn’t attend. The GPs took the lead in discussing the clinical details of patients, with the district nurse volunteering information where the patients were known to her. No referrals were made at the meeting. The district nurse at the end of the palliative care element of the meeting then produced her ‘book’ of patients to discuss, few of whom were palliative care patients. For her, the meeting appeared to be a rare opportunity to liaise with both GPs in an unhurried manner.

The difference between the observational and interview data regarding the relative key worker or leadership roles of nurse and doctor could be explained in a number of ways. It may be that nurses talk about their key worker role, but do not enact it in practice. It may also be that the behaviour of nurses in medically dominated meetings, within the practice, is very different to their individual encounters with doctors, or with their role with patients. A recent study of ‘pain talk’ in palliative care team meetings found that specialist palliative care nurses were reluctant to criticise the care of others, particularly general practitioners, in an open meeting. They used rhetorical strategies, using attribution shields such as ‘they said’, to allow them to maintain good relationships with general practitioners, and provide a platform for criticism (Arber, 2006). It may be that open communication is difficult, and this is what was being observed. It may be that there was an unspoken meeting etiquette, with the nurses generally acting as visitors to the meetings. Most critically, these meetings, although presented in the interviews as examples of good practice in referral and liaison, appeared important in discussing and reflecting on past and current care, but rarely triggered referrals, which appeared to happen outside the (relatively infrequent) meetings.

It has been argued that in home care situations formal authority belongs to the doctor, but functional authority to the nurse by virtue of their relationship with the patient (Marrone, 2003). It may be therefore that being a key worker denotes functional authority, but formal leadership authority is still maintained by others.

Doctors, by virtue of their professional culture may expect to make decisions and be in charge, and assume or be expected to assume leadership (Hall, 2005).
These issues operate in palliative care, with doctors talking about a supportive and facilitative role with Macmillan nurses, but from a position of implied superiority (Clark et al., 2002), and feeling that they should be the natural team leaders within palliative care teams when previously uni-professional nursing teams become multidisciplinary (Seymour et al., 2002a). This recognition of the leadership of medical staff has also been recognised by district nurses, with a study of teamwork in primary care finding that even district nurses who did not feel part of a primary healthcare team, often because of the attitude of the general practitioner towards themselves, still viewed the general practitioner as the de-facto leader of the team (Wiles and Robison, 1994). A recent study found that the professional position of nurses meant they felt they had less authority than general practitioners (Thomas et al., 2004).

The team working situation was therefore confused by a number of factors: the lack of a formally identified key worker; the potential confusion of multiple professionals identifying themselves as key to patient care; and the potential interrelationship of key worker and leadership roles. What impact did this sense of being a key worker or team leader have on how and why patients accessed community palliative care services? Certainly, if the interview data reflects reality, then being perceived to be the key worker appeared to allow the professional to coordinate and influence referrals. The ‘unofficial’ team leader role appeared to make little difference to referrals, as the ‘teams’ were organised around ‘team work’ with patients, rather than an organisational team. Hence, other professional issues such as relationship building, autonomy and ownership may have more of an influence on such teamwork, and therefore referral practices.

8.4 Judging other professionals

Judgements were often made about services provided and the individuals providing such services. This was particularly true looking at the division between generalist and specialist palliative care, where the existence of specialist services by definition suggests inadequacies with general services, and generalists can often be negative about the role of specialist services and the extent to which they should defer to them (Ingleton, 2000; Mitchell, 2002; McKenna et al., 2003).
In this study, referrals to others were often predicated on a critical judgement of the individual professional’s past performance, rather than the service provided per se. Such judgements also affected ongoing relationships between professionals. Inter-professional issues, or judgements of other professionals were some of the most frequently deployed codes, perhaps indicating how important these issues were to referral decision making. Such judgements made were, of course, both positive and negative.

Table 8.1 broadly indicates the balance of judgements made between the three main professional groups interviewed: district nurses, general practitioners and specialist palliative care nurses. The use of such tables to display coding frequencies is proposed for mixed methods research by Onwuegbuzie and Teddlie (2003). Such a table needs to be treated with caution, as the numbers are indicative of trends only. The number of coded segments is dependent on the number of interviews performed, the length of the interviews, and how dispersed judgemental comments were through the interviews. However, it is included here to highlight the strength of the indication that professionals appeared twice as likely to make negative comments about colleagues as positive comments. It also highlights some possible differences between both case studies and professional groupings.

Table 8.1 Numbers of positive and negative comments made about community palliative care staff within each case study site

<table>
<thead>
<tr>
<th>Profn. discussed</th>
<th>DN</th>
<th>GP</th>
<th>SN</th>
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<td>5</td>
<td>8</td>
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<td>B</td>
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<td>5</td>
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<tr>
<td>Totals</td>
<td>29</td>
<td>14</td>
<td>47</td>
<td>21</td>
</tr>
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(DN = district nurse, GP = general practitioner, SN = specialist nurse, A, B, C refers to case study site).
Further analysis of the judgements made indicated that a distinct notion of individuals as ‘good’ or ‘bad’ professionals was often discussed, with the characteristics that contributed towards these judgements varying between professional groupings. These characteristics are now discussed in more detail for the three professional groupings most likely to attract judgemental comments; general practitioners, district nurses, and specialist palliative care nurses.

**General practitioners**

General practitioners were the professional grouping who appeared most likely to attract judgemental comments, particularly from district nurses, with whom it could be argued they were likely to work most closely. Such critical comments are not new, and have been identified in other studies, particularly with reference to a perceived unwillingness to listen, to discuss issues, or to trust the judgement of the nurse (Cartwright, 1991b; Newton and Waters, 2001). The general practitioner’s characteristics most likely to arouse comment in this study were their perceived responsiveness, communication skills, and the respect they showed towards other professionals.

Responsiveness was a particular issue, with nurses often portraying general practitioners as reluctant to respond to patient need, nurse requests, or new initiatives:

‘Well some [GPs] don’t do the GSF, and won’t do the gold standards framework, some won’t provide anticipatory medication for patients who are in the terminal phases, some won’t go out and visit patients.’ (A/DN4)

‘The GPs in this area are not particularly that responsive to nurse demands. It doesn’t matter for what … there is two of them that I will ask, and know I will get, but the rest of them it depends on what mood they are in, how busy they are or whatever.’ (B/DN4)

‘Its not an easy practice to work with. It’s very hard to get the GP to go out and do a visit anyway with palliative patients. And I don’t know whether this person doesn’t feel it’s necessary sometimes to refer to us where these people who are more compassionate about the whole situation would refer.’ (C/DN5)

Others’ research with general practitioners reveals that some of the issue may be about professional boundaries, and a reluctance to accept the expertise of others outside their own profession. Evaluations of palliative care general practitioner
facilitator schemes, where general practitioners are educated by a fellow professional, have shown that they prefer to receive information from a fellow general practitioner, who is aware of their role constraints (Ingleton et al., 2003; Shipman et al., 2003; Clark et al., 2004). It may be that not having such a resource in the case study sites at the time of the study affected their response to other professional’s requests.

However, there were some professionals commenting positively about responsiveness:

‘I don’t have any hesitation in asking them [GPs] to go out, they are normally pretty good, they do respond quite quickly.’ (A/DN1)

This variation in the responsiveness and interest of general practitioners is also found in others’ research, with a study finding district nurses described different levels of general practitioner involvement in palliative care from ‘special interest, to ‘happy to go along with things’; to ‘very little involvement’ (Burt et al., 2005). In this study many of the comments around general practitioner responsiveness appeared related to communication issues, where if the nurse had an easy route to communicate with the general practitioners this had a positive effect on responsiveness:

‘I feel we have a better relationship. Some of the GPs, the GPs here, it’s much, much easier, because if they’ve got a patient in, we’ll wait for the next patient and then bob in. More difficult at the other surgery, and they won’t, they don’t like to speak to you, you have to wait till after surgery.’ (B/DN2)

Such concepts of ‘good’ and ‘bad’ doctors did not necessarily therefore relate to their technical expertise or medical knowledge, but to how willingly they acquiesce to nurses requests. Medical staff have the power to disrupt or legitimate the nurses capacity to manage the care of patients, for example by prescribing what may be suggested, or visiting when requested (May, 1992). Many professionals related these issues around responsiveness and communication to respect and trust – if a respectful and trusting relationship were developed this was likely to have an advantageous effect on responsiveness. This can be seen by the contrasting statements by one particular district nurse about the different general practitioners and practices she worked with:
'I: What is the issue with that particular GP?
C/DN5: Oh, I’m trying to be honest, but erm, I’m the Doc and I know best … I think it’s very much a, a hierarchical attitude.’

‘The doctors here would listen to what I had to say, and there would be no qualms about a visit or whatever, because they would take it from me that I have done the assessment, I know what I am talking about.’ (C/DN5)

It’s notable that, as previously highlighted, C/DN5 and B/DN2 spoke in more positive terms about the general practitioners within whose surgery they were physically based, reserving their negative or critical judgements for the general practitioners they were attached to, but not based with. It may be that the ability to form a working relationship through regular informal contact within the same working environment had a positive impact on the professional relationship, and therefore judgemental view of professionals, and hence referrals. Good working relationships have been found to facilitate referrals from general practitioners to community mental health teams or to psychology services (Hull et al., 2002; Sigel and Leiper, 2004). Working together appeared to be facilitated by physical proximity. This supports the work of Street and Blackford (2001) and Hudson (1999) who found that personal contact promoted trust. Any opportunity for communication has also been suggested to improve inter-professional relationships (McCallin, 2001).

Where the relationship with the general practitioner had significantly deteriorated, respondents appeared adept at ‘getting round’ them to achieve a particular aim. Professionals carefully presented issues to achieve a desired outcome, or bypassed ‘difficult’ professionals, and as previously discussed, it was rare to challenge another professional:

‘We just get on and do what we want to do, and we get done what we want to happen without battling against a GP who sometimes, you know it’s budget this and budget and budget that, so it’s like we don’t have any of that. Anything that we want for these patients we manage to get round and to get between us all … we are not that bothered that the GPs don’t have that big an input.’ (B/DN4)

Street and Blackford (2001) also found that nurses used strategies to ‘cut’ the general practitioner out of the assessment and prescription process, but did work together when ‘up against’ a difficult patient. They found that nurses needed to use
medical language to communicate properly with general practitioners, and this was welcomed by time pressured general practitioners.

General practitioners were often aware that their contribution to palliative care was undervalued by others. The general practitioners interviewed described a range of responses from choosing not to refer patients to specialist services to accepting their limitations and devolving care to others. There appeared to be an issue of power affecting inter-professional judgements and relationships. District nurses derived power because of their close relationships with patients, general practitioners because of their intrinsic status as doctors and prescribers. The power to prescribe was often described as a potent symbol – and frequently referred to as the only reason to continue to involve general practitioners in palliative care:

‘Certainly then if we as independent prescribers could prescribe everything, we actually wouldn’t then really need the GP because there is no problem about us referring to hospitals, no problems about us getting patients seen early, we actually don’t need the GP if they are not willing to co-operate. There is a back door to get everything done if we need it done, apart from the initial prescribing at home.’ (C/SN1)

‘Good’ general practitioners therefore appeared to behave in a way which concurred with the view of others, minimised others’ workload, and reduced some of the role restrictions of others, particularly nurses. Whilst formal referrals to general practitioners were not made by others, because they were already ‘known’ to general practitioners, such views of good and bad practitioners significantly affected the way, and whether, they were involved in the care of patients by others. ‘Bad’ general practitioners were also less likely to refer onwards to others, as in this example:

‘you go right through to the other extreme where the GP for whatever reason whether it’s that they think that managing the palliative care or this patient doesn’t mean much or whatever, but you get the referral that says “we need a mattress and a bed because this patient is dying” and they die that night, sort of thing … So, the rubbish GPs just make it very difficult.’ (C/KI3)
District nurses

The characteristics of district nurses which were commented upon differed to those discussed about general practitioners. Respondents were most likely to comment on the working practices of district nurses, their expertise, and their workloads. A particular concern was the working practices of district nurses regarding early involvement in care, where, as has been intimated, there were variations in practice:

‘Before, district nurses picked them up from the beginning, and went through the whole process, so they were just the right support visit, but apparently now they don’t like the support visits.’ (A/SN2)

In this example, the propensity of some district nurses to reject early referrals to ‘support’ patients was being criticised. The expertise, interests, and willingness to spend time with patients of some district nurses also triggered negative comments:

‘You hear cues, you pick up on cues, and you, you take them forward, and I’m not always convinced that district nurses do that, that a patient may say something, they can either block it or pick up on it, and it depends how many more visits they’ve got in the diary that day.’ (A/SN4)

‘I think when you look at the individual staff [district nurse], it comes down to where their main interests are. The ones that are interested are really keen to get in where they are really needed.’ (C/KI3)

However, despite the negative comments that district nurses frequently made about general practitioners, general practitioners more often made positive comments about their district nursing colleagues, frequently referring to the trust they had in district nursing staff to manage palliative care:

‘They will very often manage a patient almost completely; they will deal with a death at home very well I feel.’ (A/GP2)

‘They see patients more often, I think they’re a bit more proactive than what I am, so they tend to see, they tend to pick up problems that I’ve not identified.’ (B/GP1)

‘If the district nurse says to me, ‘oh, I’m worried about it’, I won’t just leave it. I trust them.’ (C/GP4)
This confidence in district nursing staff by general practitioners again appeared to highlight their functional authority, gained because of their knowledge about and relationship with patients. It was also the case that such assessment and relationship building work, if undertaken by district nurses, saves the general practitioner the work of seeing and assessing patients. This is highlighted by Speed and Luker (2006), who identify that district nurses undertook beneficial work for general practitioners, and used strategies to circumvent or subvert the process of asking for things from general practitioners. The nurses in their study used tactics to control the response of general practitioners to requests, often by highlighting the additional work (often a visit) the general practitioners would have to do if they did not take note of the nurse’s request. They found little evidence of collegiality between district nurses and general practitioners, and again highlighted what could be called the ‘formal authority’ of general practitioners over nurses in terms of Primary Care Trust arrangements, greater technical knowledge and professional status.

Specialist community palliative care staff

Judgemental comments about specialist professionals highlighted issues of elitism and the impact of their expertise. This was particularly evident in the comments made about the community Macmillan nursing service in case study A, where the service provided by the nurses who had recently left was highly criticised by others:

‘They’d rather go off and work in a team where they can be [sarcastic tone] proper specialist palliative care people, and restrict the numbers of patients they see, and put in special referral protocols, so they, they don’t necessarily see everybody, and they become elitist about the care they offer, and all of that kind of thing, that specialist palliative care people do … ultimately when that kind of relationship with the Macmillan nurses is going on, I mean ultimately you kind of forget to refer.’ (A/GP3)

‘I think they were completely rigid in their ideas of how specialist palliative care was, they were the elite, and you know they would do what they wanted.’ (A/SN1)

In contrast, there were no negative comments made about the community Macmillan nurses in case study C, who appeared to work hard on developing a relationship founded on their referral etiquette with the generalist professionals
with whom they worked. Some adverse comments were made about specialist professionals in case study B:

‘I don’t refer patients directly to the Macmillan nurses, don’t know, don’t know what they can offer that I can’t.’ (B/GP1)

‘I know that the hospice at home team have struggled in the past to almost make a role for themselves, I think sometimes the district nurses have said, well, what are they doing, they are just duplicating what we are doing.’ (B/SN2)

Criticisms of specialist services by general practitioners were also highlighted by Cartwright (1991b) who found general practitioners were less likely to want specialist palliative care services, feeling they hadn’t the knack of liaising with general practitioners, and were over confident, wanting to rush in. District nurses have also been found to be resentful of specialist palliative care nurses, fearing an erosion of their own role (Haste and Macdonald, 1992). It is notable that the findings of this study are similar, almost 15 years later.

The differences between the case studies highlighted the contextual differences between what appeared, to an outside observer, to be virtually identically provided services. However, it was the approaches of the different individuals within those services, and the impact this had on the culture within their teams which appeared to have made such a huge difference to referral practices – to the extreme of the almost complete sidelining of a service in case study A, which appears so important to many of the professionals in case study C, for example:

‘We have a very good rapport with the Macmillan nurse to the point where if anything we tend to accept her advice, we are probably the ones asking her more, you know, and going along with what she says because obviously I know, and I have worked with her for years.’ (C/DN5)

When discussing these specialist nursing services, there was little talk by respondents of the impact on patients of the specialist services. What appeared more critical was the relationship which existed between the professionals – be it a difficult relationship based on poor communication and trust, or a facilitative relationship based on mutual respect and trust. Other studies found that general and specialist palliative care professionals can adopt a ‘them and us’ mentality, especially where there are communication breakdowns and over-stressed
services (Burt et al., 2005), and that palliative care nurses produce talk in which professionals who do not work in the same settings are constructed as ‘others’ (Li, 2005).

Such judgemental attitudes regarding other professionals coloured a lot of the discussion regarding professional relationships, working patterns and the way referrals were made. Having a negative view of the personality, working patterns, or competency of someone adversely affected the likelihood of making a referral, as highlighted above; ‘ultimately you forget to refer’. Knowing about the impact of such judgements makes the drive to maintain (or bypass) professional relationships more understandable, as being perceived positively had an impact on both relationships and referrals.

**General influences on judgements**

Theoretically, it is unsurprising that respondents had a tendency to make negative judgements about the actions of others. There are clear indications, particularly in psychological literature, that people are more likely to attribute positive events to themselves, and dismiss negative events as attributable to other causes or people – the ‘self-serving attributional bias’ (Mezulis et al., 2004). People tailor their judgements of others to affirm their own self-worth, and make sure their evaluations of others place themselves and their own attributes in a positive light (Beauregard and Dunning, 1998). Indeed, such self-affirming behaviour also appears to extend to the groups which people consider themselves to be part of, making judgements that favour their groups (Sherman and Kim, 2005). Beauregard and Dunning (1998) also suggest that people make more derogatory comments about ‘outgroups’ when their own esteem is threatened.

In addition to these self and group serving behaviours, there is strong evidence that people perceive their own actions in a different way to those of others. It is suggested that people consider their own behaviour to be influenced by the situation and the pressures exerted by circumstances, whereas they are more likely to believe the actions of others are influenced by stable trait dispositions such as their character or temperament (Watson, 1982).
These theoretical perspectives appear to be supported by these findings. For example, the ‘outgroups’ are referred to above as lacking in expertise, as elitist, or uncooperative, all more stable trait dispositions rather than being influenced by a particular situation. These insights may help to understand the behaviours and judgements described in this section, but do not negate the impact that these actions had on referral practice.

8.5 Summary

This chapter highlights the critical impact of inter-professional teamwork, relationships, and appreciating the work of others on referral practices.

Professionals appeared more likely to refer to others when they understood the role of the person to whom they were referring and more particularly the strengths and weaknesses in the way that individual performed the role. Referrals were then made in a way which both complemented the strengths and weaknesses of the referrer and the professional to whom the referral was being made. However, if the judgement made about the professional to whom the referral may be made was negative, this appeared to affect whether and when a referral was made.

Concepts of team and teamwork also had an impact on referral practices. Team, to the respondents in this study, appeared to principally refer to those with whom they were based, frequently from the same professional background. For teams, formal referrals appeared less frequent, as information was passed informally about patients. Teamwork seemed to relate to groups of professionals who came together to care for an individual patient, with this grouping facilitated by formal referrals. Referrals were therefore one pre-requisite of teamwork, and if not made blocked access by patients to this form of care.

However, making referrals, and hence teamwork, also appeared to be influenced by professionals’ inter-personal relationships. That there were inter-professional differences should perhaps not be surprising, as practitioners from different disciplines, with different histories, experiences and interests are likely to understand practice problems and situations in different ways. Referrals looked more likely if the professionals involved had developed a good relationship based
on working together satisfactorily in the past. Professionals therefore worked very hard to maintain good relationships where possible, sometimes compromising some aspects of the care of current patients to facilitate future referrals and care. If a good working relationship appeared not possible, then referrals tended not to be made, and alternative ways of providing needed care explored, or care restricted to a few professionals.

It appears that referrals are again not made purely on an appraisal of some measure of patient need, but are significantly influenced by the way professionals interact with and judge each other.

These three findings chapters explore the impact of context, of referral practices, of professionals’ perceptions of their role in palliative care, and the way professionals work with each other on how and why referrals are made within community palliative care services. These themes are now drawn together and conclusions made with reference to the theoretical propositions developed during the course of the study.
Chapter Nine

Discussion and Conclusions
9.1 Introduction

This chapter briefly reviews the thesis, presents the theoretical propositions developed during the study, and discusses the main findings and associated theoretical propositions with reference to theory and policy. The strengths and limitations of the research and the method chosen are debated, and its contribution to knowledge assessed. Overall conclusions and recommendations for further research are made, and implications for practice identified.

9.2 Review of the thesis

This thesis is based upon an interest in what influences how and why patients access community palliative care services. Access to such services may be a precursor to the provision of the best possible care for those in the palliative phase of their illness. Equity of access according to clinical need is a central concept upon which the provision of healthcare in the UK is based, and yet evidence suggests that, certainly within community palliative care services, this goal may not be met.

The literature reviewed in chapter 2 provides some understanding of where inequities lie. It is clear that patients are often referred to services close to death, which may be too late for them to benefit fully from the care provided. Not all patients who may benefit from palliative care services are referred, as no service studied cared for all potential palliative care patients. It also appears that patients with particular characteristics are less likely to access palliative care services. For example, those who are older, those from black and ethnic minority communities, and those who with terminal illnesses other than cancer are all less likely to receive care from palliative care services. The bulk of the literature in this area describes apparent inequality in service utilisation, but does not aid our understanding of why such inequalities exist. Understanding the reasons for such apparent inequalities is a first step towards addressing them. There is an emerging literature exploring professional and patient related barriers to referral. This indicates that professional knowledge about services and the attitudes of patients and professionals towards services may have an impact on referral practices. The research reported here sought to improve understanding of what influenced professionals’ decisions to refer.
This research investigated the influences on referral decisions made by providers of community palliative care services within the context of different services. A qualitative case study strategy was chosen as the research approach as it provided a framework for facilitating the incorporation of multiple perspectives in a complex context, in a field where there has been little previous research, and where there is little theory to guide the investigation. Three cases (Primary Care Trusts) were studied. Data collection incorporated interviews, observation and documentary analysis, as well as mapping and profiling the palliative care services provided within the cases. Detailed data analysis followed a framework approach, comparing and contrasting patterns within and across cases with existing and developing theoretical propositions.

Four findings chapters are presented. In Chapter 5 the context of the cases studied is described, drawing out the similarities and differences between the Primary Care Trusts in their provision of palliative care services, and providing a background against which the three further chapters reporting cross-case findings are discussed. The systems of palliative care in the cases shared some similarities in the way district nursing and general practice services were organised and provided palliative care. However, their approaches to the provision of specialist palliative care services differed, ranging from a small nurse led service in one case, to a comprehensive multi-disciplinary hospice based service in another. Even with these substantial differences in the context of care within the cases, it appeared from the data that common issues drove the making and receiving of referrals.

Chapter 6 describes the way health professionals explain referral making processes. Physical, psychological and social reasons for referral appeared to be the foundation for making and receiving referrals and were the shorthand language professionals used to describe referral making. However, there also appeared to be complex professional rationales for referral, which are not necessarily encapsulated within such formal ‘reasons for referral’. These rationales are explored further in chapters 7 and 8.
Chapter 7 explores the impact of professionals’ perceptions of their own role on referrals within community palliative care. The reasons for referral appeared to be filtered by the professional to judge whether a referral was warranted for that particular patient, in that particular caring context, and to meet the particular requirements of the referring professional. The needs of the referring professional appeared to sometimes take priority and a sense of self-determination and the relatively ‘invisible’ nature of caring in the community allowed professionals to determine such priorities often without recourse to others. The relationships which professionals often developed with patients affected these referral judgements, as did the perceived added value of the referral in buying time and expertise, controlling their workloads, or meeting professionals’ emotional needs.

Chapter 8 presents data exploring the impact of professionals’ views of others on referral making. Inter-professional relationships appeared critical to referral decision making, with professionals more likely to refer when they both understand the role of the person to whom they were referring, and personally knew and valued their approach to care. Conversely, a negative appraisal of a professional, often based on a difficult working relationship, was likely to restrict referrals made and affect the way they were accepted.

The data clearly suggest that many more factors than an assessment of patients’ clinical needs affect referrals within community palliative care services. It seems that personal, inter-personal and inter-professional factors have the potential to shape referral practices. It is likely that the combination of these factors has an influence on equitable access to community palliative care services.

These findings were continually used to revisit the initial theoretical propositions. The theoretical propositions developed from this study are now presented.

9.3 Theoretical propositions

Four initial theoretical propositions are presented in chapter 4. These were critical to guiding data collection and analysis, and are presented below.
1. Professional roles and responsibilities are constantly re-negotiated around the care needs of individual patients.

2. Caring for palliative care patients is ‘special’ and the status this confers on professionals affects the referral choices they make.

3. Professionals have a sense of ownership and responsibility towards palliative care patients, and this affects their gate keeping role in referral to and work with other professionals.

4. The culture and context of individuals, teams, and organisations providing palliative care will affect referral patterns.

Throughout the process of data collection and analysis these propositions were constantly interrogated and amended, and new propositions developed. This was an iterative process, with many intermediate steps. What are presented here are the final theoretical propositions which emerged at the end of this process, once data collection and analysis was complete.

Three overarching theoretical propositions were developed, relating to the core issues of making and receiving referrals within community palliative care services, and the context within which these referral decisions occurred.

1. **Referrals are made following a complex appraisal of the referral situation, not purely a patient’s clinical need.**

This appraisal takes account of

- The needs of the referring professional, including their emotional capacity, expertise, time available, and interest in palliative care.
- The health care professionals’ interpretation of patient preferences, including an appraisal of their fears about referral.
- The clinical needs of the patient. Formal reasons for referrals are framed by reference to a bio-psycho-social model of care, although there is no ‘absolute’ definition of clinical need in palliative care which triggers a referral.
- An appraisal of the professional/service to whom the referral is made, including what they can offer to the referring professional in...
terms of time, expertise or teamwork, and a judgement about their previous input with patients.

- The relationship with patients and carers which can create a sense of ownership that restricts or facilitates referrals

2. **Referrals are acted upon following an appraisal of both referral information and the person making the referral.**

This appraisal takes account of

- A judgement about the knowledge, skills, expertise and interest of the person making the referral.
- Any potential need to compensate for perceived gaps in care.
- An interpretation of the perceived appropriateness of the referral.

3. **Referral decision making is influenced by factors which affect the professionals’ perspectives about their work.**

- A sense of autonomy, self-determination or the independence of clinical judgement allows professionals to make referral judgements independently, not necessarily according to local or national policies.
- An individual’s interpretation of and approach to their role is more important than the role itself in determining referral patterns.
- Maintaining a relationship with fellow professionals to facilitate future care and referrals can be as important as care of current patients.
- Palliative care is ‘special’ and ‘important’ work which allows usual approaches to care to be suspended.
- Specialist palliative care services involvement with patients is not mandatory, and so their use is carefully negotiated.

These theoretical propositions encapsulate the core influences on referrals revealed in this study. These propositions, amended with reference to data from three cases, hopefully allow what has been called ‘analytical generalisation’ or the similar concept of ‘theoretical inference’. Theoretical inference is a form of generalisation from case studies where conclusions are reached about what
usually happens in a certain type of theoretically defined situation (Gomm et al., 2000). Analytical generalisation is where a developed theory is used as a template against which to compare the results of the case study; if two or more cases support the theory replication may be claimed (Yin, 2003a). The propositions developed should facilitate such generalisation.

9.4 Discussion

The discussion focuses on bringing together themes and theoretical propositions presented in different chapters, and relating them in an integrated manner to existing theory, practice and policy.

Theoretically, access can be affected by different factors including user issues, professional issues and organisational issues (Gulzar, 1999). In this study, the issues which appeared to have the greatest impact related to professional factors: the impact of the way referrals were made, interpreted and received by professionals working in community palliative care. These factors are discussed and related to previous research in chapters 6, 7 and 8. In this chapter the following underlying issues are discussed in relation to theory, practice and policy: the importance of professional autonomy and professional judgement to allow professionals to work as independent practitioners and make self-directed referral decisions; and issues of teamwork and collaboration affecting the way professionals work together and refer to each other.

9.4.1 Professional judgement and autonomy

The operation of the first two theoretical propositions demands that professionals work from a position of relative independence or autonomy in the exercise of their professional judgement. To act upon a personal assessment of whether referral is needed requires, for example, the person making that judgement to have the capacity and authority to make such a decision. These issues are particularly highlighted in chapter 6, where the impact of professionals’ sense of autonomy on referrals is discussed, but appear to have an impact on the way many other factors operated. The impact of such professional judgement and autonomy is discussed
in two main areas; judging what is ‘good practice’ in referrals and care, and the interrelationship of judgement and policy.

**Good practice in referrals and care**

The place of judgement in palliative care decision making is explored by Bliss and While (2003). They suggest that at each stage of the decision making process judgement is used to progress to the next stage. They recognise that judgement is affected by many issues such as the different paradigms of professionals, the use of previous experience and how important this experience is to the person making the judgement. That there are such different influences on judgements indicates that inevitably the judgements themselves will differ, and therefore begs the question about whether the judgement made is ‘right’ or ‘wrong’. That there are differences in opinion between professionals in this study is discussed in chapter 8, where differences in opinion between professionals led to adverse judgements about others, which in turn impacted on the choices made in referrals.

It is probably fair to say that most, if not all, of the professionals involved in making and receiving referrals within this study appeared motivated in their referral choices and judgements by a sense of concern for and interest in the welfare of patients and their carers. Whether this has an implication for the study is considered later. However, for all professionals, whether the referral choices they made were perceived as ‘good’ or ‘bad’ depended on the differing perspectives of themselves and others, not necessarily an explicit, generally agreed notion of what might be right or wrong for palliative care patients. It could be argued that the definition of palliative care presented in chapter 1 may provide a practical framework for ‘knowing’ whether a particular judgement about referral or care is ‘right’ or ‘wrong’. However, whilst this definition outlines an approach to palliative care, it does little to explore how this may be put into practice. Whilst some of the suggestions for a team approach to care, or an acknowledgement of the benefits of early care may imply a particular way of caring, the way this is translated into practice by organisations, teams and individuals could be a matter for debate.

Efforts have been made to define good practice in palliative care provision. Guidance for commissioners suggests the service elements which should be in
place to provide 'good' palliative care (Tebbit, 1999). A service model for palliative care provision in England has also been proposed within the NICE supportive and palliative care guidance (NICE, 2004). It suggests for example that some patients need a range of specialist services, the importance of forging partnerships, and the value of such partnership in achieving effective multi-agency and multidisciplinary team working. It recommends that mechanisms should be developed to promote continuity of care, which might include the nomination of a person to take on the role of key worker for individual patients (p 6-7). Such proposals appear to lack awareness of the complex and subtle influences on referrals and teamwork which respondents in this study described. They also appear insufficiently specific in their recommendations to indicate to professionals that changes in current referral practices may be necessary, for example towards referrals to specialist services where they are not currently perceived as necessary. Because such policies do not reflect the reality of day to day practice highlighted by the findings from this study, they may not have the desired impact on practice.

Perhaps of more concern in terms of referral practices, is that research has yet to demonstrate what ‘best’ referral practice is. The definitions, commissioning recommendations and policies referred to above may imply particular practices are superior, but this is not supported by sufficient evidence. There are three gaps in the current evidence base. First, generally the research reviewed in chapter 2 describes whether or when a referral was made, not the outcome of the referral. Second, whilst there is work investigating the outcomes of care, determining optimal palliative care is difficult, with relevant care outcomes hard to establish or measure (Hearn and Higginson, 1997; Hearn and Higginson, 1998; Higginson et al., 2003; Aspinal et al., 2003). Third, most of the research reviewed investigates referrals to, or outcomes of care from specialist palliative care services, and it may be that patients receive satisfactory care from generalists without such referrals. There is little research into the outcomes of care when patients receive care from generalists as most research investigates the outcomes of specialist care, without reference to generalists (Hearn and Higginson, 1998).

The implication of these gaps in evidence when taken in conjunction with the findings of this study is that it is not possible to say whether the varied approaches
to referral practices facilitated by the relative autonomy of the professionals within
the study were ‘good’ or ‘bad’, ‘right’ or ‘wrong’, just different. Whilst they were
judged as such by their fellow professionals, such intuitive judgements were not
necessarily made on an appraisal of patient experience or outcome, but more
commonly on the impact of such referral practices on their own care.
Recommendations for particular referral practices therefore cannot be made from
this study. It is recommended that future palliative care policies take account of the
influences on such practices described in this study, and recognise that simply
mandating referral, partnership or teamwork for example is unlikely to change
practice in the desired direction.

Judgement and policy

Gaps are exposed in this research between the policies, guidelines, and other
documents designed to influence professionals’ approach to referrals and the
actual way they articulated referral practice. The difficulties of implementing clinical
guidelines are well rehearsed, and it is known that any change in professional
behaviour requires comprehensive multiple approaches tailored to different
groups’ needs (Woolf et al., 1999; Smith, 2000; Grol and Grimshaw, 2003).
Professionals are argued to operate on the basis of micro-level concerns, using
practical mechanisms through which they deliver care to patients (Armstrong,
2002). Armstrong (2002) suggests that the logic of evidence based medicine, the
focus of much current policy and guidelines, is inimical to the individual
professional autonomy emphasised within a ‘patient centred’ approach. The
centrality of referral decisions based on an individual knowledge of and
relationship with patients rather than protocols or guidelines was found in this
research, and reported in chapter 7. It may be that this approach grounded in the
immediate concerns of patient, family and professional superseded the influence
of guidelines or policy imperatives.

No unifying theory to guide understanding of health professional behaviour change
has been identified, and there are many different theories which could have utility
in explaining how behaviour may be influenced (Smith, 2000). However, the focus
of this study is on describing how referrals are made, and the influences on such
referrals, and one concept which appears to have value in understanding the way
professionals enact policy in practice, rather than explaining behaviour change ‘towards’ a desired behaviour, is that of professionals acting as ‘street-level bureaucrats’ (Lipsky, 1980).

Lipsky (1980) argues that front line public servants exercise power by making and implementing policy. Characteristics shared by street level bureaucrats include; a focus on the need to process workloads quickly, substantial autonomy in their individual interactions with clients, an interest in maintaining and maximising that autonomy, conditions of work that include inadequate resources (money, resources, time), demand that will always exceed supply, ambiguous and multiple objectives, difficulties in defining or measuring good performance, a requirement that decisions should be taken rapidly and clients that are ‘non-voluntary’ – they have limited choice over whether, where or how they present to the service involved. Faced with demands of work situations they will inevitably ration services, either by using devices such as waiting times, or gate keepers, or through having psychological costs associated with seeking help. Faced with inadequate resources, high discretion and conflicting objectives, ‘the decisions of street level bureaucrats, the routines they establish and the devices they invent to cope with uncertainties and work pressures effectively become the policies they carry out’ (Lipsky 1980 p12).

Whilst there are other theories which address the work of professionals and the way they exercise power (see for example the work of Freidson (2001) regarding medical self-regulation), the findings of this study appear to have particular resonance with the concept of ‘street-level bureaucracy’. It appears that many of the professionals involved in this study shared the characteristics of ‘street-level bureaucrats’. Certainly autonomy in their individual interactions with clients is discussed in section 7.2, difficulties with workload and resources in 7.4 and 7.5, and patients appeared to have little choice in how they accessed services (section 6.3.6.). An example of a policy interpreted in different ways by the respondents in this study according to the contextual demands of the situation is the Gold Standards Framework, where the policy expectation of early referral did not always happen if the ‘street-level bureaucrat’ had concerns about the impact on their case or workload.
General practitioners have been identified as ‘street-level’ bureaucrats in the work of others (McDonald, 2002; Checkland, 2004). The evidence from McDonald’s (2002) study suggests that general practitioners continued to exercise clinical judgement rather than follow central guidance, aided by a work context where actions were largely not open to scrutiny or peer review. This gave them huge discretion in the way they performed their work, and allowed them to focus on elements of care that were relevant to their own work environment, findings which resonate with those of this study.

The ability to act as ‘street-level bureaucrats’ and to exercise professional judgement about referrals in a way which is rarely challenged by others has significant implications for palliative care practice and policy. For example, the ‘Improving supportive and palliative care for adults with cancer’ guidance argues that there is a need for improved patient assessment to help overcome barriers, including poor referrals, to the provision of services for patients and carers (NICE, 2004). Assessment tools have therefore been developed, with one aim being to improve referral practice (Ahmedzai et al., 2003; Ahmed et al., 2004; NICE, 2004; Richardson et al., 2005). However, assessment competence, whilst perhaps an element affecting adverse judgements of others or failure to recognise need to refer, was not reported as a major barrier to referral within this study. Therefore, even an accurate and expert assessment of patient need may not lead to referral to other services if the individual autonomous judgement of the assessing ‘street-level bureaucrat’ is that they can, for example, meet the needs of the patient without referral, or that the services they may wish to refer on to have not met their needs in the past.

The exercise of autonomous clinical judgement appears to have an important effect on referral practice. Whilst there could be a presumption that some of the variation in referral practice that such autonomy generates is inappropriate, such practices are rarely challenged. This discussion has highlighted two reasons for this: that best referral practice has not been described or proven; and that changing referral behaviour is difficult because of the multiple, subtle, and often unrecognised influences on professionals.
Practitioners could be more explicit about their referral behaviours, justifying to themselves, other professionals, and patients why they are making particular choices. Referral policies need also to recognise the breadth of influences on referral, and could explain in more detail local referral expectations such that exceptions to this can be more easily highlighted and debated. Best practice in understanding how to influence professional behaviour should also be attended to, with multiple interventions to effect change planned alongside such policies. Without such overt awareness and discussion of variability there are potential risks to clinical care, and threats to clinical governance.

Professional judgement and autonomy is therefore an issue which affects the operation of referrals within community palliative care services. A further overarching factor is the way professionals collaborate to provide care.

9.4.2 Collaboration, teamwork and partnership

The concept of team appears very important within palliative care, with multiple references to teamwork, collaboration and partnership in the literature. A team approach is a component of the definition of palliative care discussed in chapter 1, and partnership is promoted as a valuable way of achieving effective multi-agency and multidisciplinary team working in the NICE supportive and palliative care guidance (NICE, 2004). There is a clear assumption that interdisciplinary collaboration will bring about more efficient and effective work and consequently that patients will receive better care (Farrell et al., 2001). However there is little evidence to support this. The NICE supportive and palliative care guidance, despite recommending teamwork, admits that few studies have examined the impact of communication, coordination and continuity of care, or lack of it, on the process and outcomes of care (NICE, 2004).

The evidence within this study, particularly the data presented in section 8.3 exploring professionals' perceptions of teamwork, is that teamwork is a positive experience for professional and patient ‘when it works’. However, the data also showed that professionals perceived themselves to be providing a good quality of palliative care when there was no team approach, and no referrals to other services had been made. This highlights the difference between formally
constituted teams (such as the district nursing teams) who worked as a team irrespective of referral making behaviour, and informal team-working created by a network of referrals. Hence referral is a pre-requisite to much teamwork and team formation, but appears not always to be necessary to the perception of good quality care provision.

The recognition that a team approach (between professionals, or involving generalist and specialists) may not be necessary to provide good quality palliative care could be for several reasons. First, professionals may feel it is not necessary to supplement the care they offer. This may not be a wholly unreasonable perspective since there is little evidence that not referring to or working in teams is necessarily deleterious to care. Second, it could be triggered by a tacit acceptance that teamwork requires effort and work, which may be an unacceptable investment in time or energy.

The costs and difficulties of collaboration have been noted by others. Collaboration is described as a complex sophisticated process occurring between individuals, not institutions, so only the persons involved can ultimately determine whether collaboration happens (Henneman et al., 1995). Henneman et al., (1995) also critically recognise that collaboration is often related to work between potentially adversarial groups such as doctors and nurses. These statements imply that collaboration between such groups is difficult, and reliant upon the views of the individuals concerned.

More broadly, a review of theoretical and empirical studies identifies interactional, systemic and organisational determinants of collaboration (Rodriguez et al., 2005). The research reported within this thesis identifies a number of issues which could influence these determinants: the autonomy and judgement discussed earlier, the negative appraisal of some fellow professionals, a lack of belief in the advantages of working with others, a lack of understanding of what others do, a lack of physical proximity in the work place, a lack of team resources such as time, and a lack of shared documentation. These are likely to be major obstacles to teamwork or collaboration, affecting the referrals which create such teams.
Where referrals are made to pass on the patient to others to control workloads, then such teamwork influences may not affect practice. However, if referrals are made to bring an informal team together to care for a patient then these factors affecting collaboration and team working would also affect referral practices. For practice then, referrals do not just raise issues of identifying which patients may benefit from other services and an individual’s competence to care, but identify fellow professionals with whom collaboration or teamwork may be possible. Practices which understand this dynamic are therefore necessary, not purely those which promote better assessment of clinical need. Referral practices are likely to be affected by moves which promote teamwork such as basing people more closely together and facilitating informal socialising, sharing documentation, and engaging in joint educational opportunities.

The team dynamic which may underpin referral practices within community palliative care appears to set this work apart from the work of some others investigating referral practices. There is a substantial literature for example examining the variation in general practitioners’ referrals to specialist hospital care (Wilkin and Smith, 1987; O’Donnell, 2000). Factors studied to explain this behaviour include examining patient characteristics, general practitioner characteristics, practice characteristics and access to care. Theoretical models to explain the decision making process have been described which focus on issues such as general practitioner cognitive processes, confidence in clinical judgement, resources, and the context of the referral (Dowie, 1983; Wilkin and Smith, 1987; King et al., 1994). Many of the factors in each of these models appear supported by this community palliative care specific research. However, these models do not highlight the importance of the teams and their relationships created by referral found in this study.

There are also implications for policy, as it has been highlighted in other fields that policies which promote partnership, collaboration or teamwork pay scant attention to tensions that exist between professional groups, and espouse a form of collegiality which has seldom existed (Speed and Luker, 2006). It has long been recognised that the policy imperative has been optimistic regarding partnership, presuming both rationality (that collaboration will happen by showing that same ends will be achieved better together than separately) and altruism (to collaborate...
purely for the good of the community they serve) (Hudson et al., 1999). However, not only is such partnership or teamwork difficult to achieve, it may not be the only or best way to deal with a particular issue (McLaughlin, 2004). These issues are certainly supported by the data in this study, with, for example, examples of referral behaviour which did not show the presumption of rationality or altruism suggested above, and which appeared (to the professional respondents) to achieve good care nevertheless.

Partnership or teamwork can be an important solution to particular problems, but they may not always be the only or best solution for the individual or the organisation. Palliative care policies could take note of these issues. It may be that recommendations of partnership, teamwork or collaboration should only be made where a clear benefit can be shown, or where there are minimal costs involved.

9.4.3 Professional relationships

Related to, but distinct from, the concepts of teamwork and collaboration apparent in the data are concepts of inter-professional relationships and their effect on referrals. The data regarding such relationships are mainly presented in sections 8.3 and 8.4. Two issues emerging from the data and which are also reflected in theory and literature are the relationships between generalists and specialists, and between doctors and nurses, and these are discussed further here with reference to their effect on referral making.

*Doctors and nurses*

The classic model of the doctor – nurse relationship was first proposed by Stein in the late 1960s, and later modified as professional relationships changed and developed (Stein et al., 1990). In this model nurses exert influence by manipulating doctors, without challenging the fundamental asymmetry of the power relationship. In recent years however this hierarchical and structuralist model has been criticised for lacking subtlety and not being relevant to contemporary healthcare (Svensson, 1996; Allen, 1997; Speed and Luker, 2006). More recently a negotiated order perspective (Strauss, 1978) has been used to illuminate issues surrounding this relationship (Svensson, 1996; Allen, 1997;
Speed and Luker, 2006). The term ‘negotiated order’ was first used to conceptualise the ordered flux found in studies of hospitals. Recent studies in hospitals have found that the conditions for inter-professional negotiation have altered fundamentally, augmenting the influences of nurses (Svensson, 1996). Svensson (1996) feels there are key changes in the negotiation context which have given nurses space to directly influence patient care decisions; the increase in long-term health problems in which nurses are well placed to contribute to patient management; and changes in nurse management which facilitate direct nurse – doctor communication.

A relevant critique of this perspective is that the majority of the work has been undertaken in hospital environments, and that work in primary care may be very different. Recent research studying the interplay between district nurses and general practitioners demonstrates two dominant discourses – that general practitioners construct the district nurse as an employee, and also have a sense of technical and professional superiority (Speed and Luker, 2006). This power and control led to resistance, seen in their study as covert subversion and subtle manipulation by the district nurses to pre-empt non-cooperation. They also identify however that where nurses perceived themselves to have technical competence, they could and did challenge the authority of the general practitioners, with end of life care given as a specific example.

The complexity of these power and control relationships between doctors and nurses is highlighted in the present study, with nurses reporting subtle interactions with doctors to maintain working relationships whilst achieving desired aims, subverting medical authority by bypassing normal procedures, and yet appearing subservient in their observed interactions with doctors. Specialist nurses also describe using similar tactics, but because of their superior (technical) knowledge appear able to challenge doctors more successfully. The desire by nurses to develop a strong relationship with patients could be seen as a way of nurses achieving superior (social) knowledge to doctors as a way of addressing the power relationship between the two professionals. Nurses also undertake service work for doctors – in this case the regular supportive visits and care, however this work didn’t negate conflict, for example, when nurses attempted to blur the nurse doctor
responsibilities by recommending ‘prescriptions’, which they lacked the authority to do without medical input.

In this study there are therefore examples of complex and subtle negotiations between doctors and nurses, indeed between all professionals. Some negotiations appear tacitly understood by many respondents, for example the unwritten etiquettes around referral order which many discussed. Other negotiations differed on a case by case basis. Such negotiations appeared to be highly influenced by the judgements professionals made about each other. Particularly notable were the mainly negative judgements nurses made regarding doctors. These negative judgements appeared commonly in nurse discourses, particularly about general practitioners, and seem ‘acceptable’ because they were so regularly made and shared. Such judgements often related to whether general practitioners concurred with nurses, with nurses frustrated when their wishes were sidelined, possibly reflecting a lack of power to change or control this situation. This may be a reason for ‘back-door’ autonomy, where nurses achieve desired aims by bypassing ‘difficult’ professionals, rather than challenging the autonomy, decisions or power of others.

**Generalists and specialists**

The potential for a lack of collegiality was present in some relationships between doctors and nurses in this study, and was also seen in the way that generalists and specialists worked together. Almost by definition, the presence of a specialist implies some deficit on the part of the generalist to provide sufficient care, and this could create an inherent tension in the relationship. Other studies support this concept of tension with a study of district nurse and general practitioner perceptions of specialist nurses finding much negativity about specialism and concerns about role conflict, role overlap and role confusion (McKenna *et al.*, 2003). A lack of role clarity about the roles of generalist and specialists has also been found in service providers and commissioners (Payne *et al.*, 2002).

This lack of clarity about the roles of generalists and specialists is unsurprising when the different roles adopted by specialist providers are examined. Research
shows that specialist palliative care services in the voluntary sector are seen variably as substituting, complementing, supplementing and duplicating the services of the primary care team (Robbins et al., 1996). Such different perceptions of roles were found in the research reported in this thesis, although the perceptions related not to services per se, but to individuals and their characteristics and skills. Such variable and sometimes negative relationships between generalist and specialist inevitably led to several suggestions that the role of specialists could be reduced.

There is an increasing emphasis on the role of generalists in providing community palliative care, and for their expertise in palliative care to be recognised, supported and extended. Part of the rationale for the recent policy of investment in district nurse education in palliative care has been recognition of their importance in providing care (Hughes et al., 2006; Addington-Hall et al., 2006). A strong argument for extending the role of district nurses and general practitioners in providing community palliative care services has also been made (Murray et al., 2004). Murray et al. (2004) argue that the values of holistic patient centred care that primary care professionals share with palliative care specialists were first promoted within primary care. They suggest that general practitioners and district nurses are trusted by patients and are in a position to provide effective, equitable and accessible palliative care for most patients.

A logical extension of the argument that the skills of primary care professionals are well suited to the provision of palliative care is to question what specialist palliative care can add. The popular perception that specialist care is ipso facto superior to generalist care is a powerful one – despite a lack of evidence of difference in processes or outcomes (Fordham et al., 1998). Fordham et al. (1998) question what makes palliative care distinctive as a speciality, when it claims to be driven by a philosophy that potentially excludes nobody and includes everybody, and which eschews reference to any specific disease category.

There are real tensions between an evidence base in palliative care which almost exclusively looks at the impact of specialist palliative care on outcomes, reinforcing an idea of the superior nature of specialist palliative care, and an increasing clamour from generalists for their role in providing community palliative care.
services to be recognised. The data in this thesis support the existence of these tensions between generalists and specialists, and highlight the impact these tensions may have on referral practices. Certainly, whilst referrals to specialist palliative care services were sometimes positively discussed, there were also clear indications of referral decisions which excluded specialist care.

**Policy and practice**

That there are sometimes difficult relationships between doctors, nurses and other professionals, and between general and specialist staff seems clear from both this and others’ research. The background issues affecting relationships are complex, affected by such considerations as power, status and role. These relationship issues appear critical to the way that professionals make referrals within community palliative care services. Changing referral practice affected by such complex issues is likely to be difficult, and simple solutions such as better assessment and referral criteria, or clearer referral policies are unlikely to have a lasting effect.

One potential long-term solution could be to reduce inter-professional barriers early in professional careers with shared education between professionals. Much of the literature concerning inter-professional education explicitly states that cultivating collaboration is one of the main foci, as well as individual professional preparation and improving services (Barr *et al.*, 2006). Barr *et al.* (2006) suggest these aims are interdependent, such that inter-professional personal preparation drives effective teamwork which drives changing services and care. Research on inter-professional education with established community teams found an improvement in team working, but also that there were slippages in team functioning over time, some related to institutional constraints, but also more personal reasons such as gravitating to ‘old’ ways like putting self protection and self interest first (Cashman *et al.*, 2004). It may be that shared education could be helpful in affecting professional relationships and hence referral practices, but that sustained efforts are required to maintain change.

The current practice of specialist palliative care being negotiated and ‘invitational’ can also be questioned. It seems that the question of whether specialist palliative
care should supplant, supplement or support the care of others is not yet answered (Payne, 1998). Specialist practitioners in this study demonstrated taking all three roles at times, moulding interventions according to their judgement of the competency of the general professional. Whilst this may be in tune with the ‘levels of intervention’ promoted for use within specialist nursing (Webber, 1997), respondents in this study reported more covert appraisal, rather than overt, mutually acknowledged level of intervention. Policies which promote open awareness between professionals of the existence and needs of patients may go some way towards breaking down some of these barriers. Whilst issues of confidentiality are important, systems which allow information sharing without formal referral may break down some of the current barriers about ‘knowing’ who patients are. Whilst the evidence of this study suggests that some professionals may not respond to such ‘knowing’, such systems may go some way towards affecting referral practice.

One reason why palliative care referral practice may highlight some of these inter-professional issues is the value professionals place upon providing palliative care to patients and carers. The provision of palliative care appears to both confer status on professionals, and make them feel valued and useful. Such feelings are likely to affect personal interpretations of any policy or practice related changes to referral practices, and should therefore be considered in their implementation.

9.4.4 Equity

Much of the literature reviewed in chapter 2 documents differential access to palliative care services for patients with different demographic, social and disease characteristics. However, such issues were rarely raised in this study.

There could be several explanations for this. It may be that patient characteristics do impact on referral decision making, but that professionals chose not to discuss these factors, or that I as interviewer accepted unchallenged the superficial accounts of respondents. Interviews, observations and documents reveal a particular version of reality, one which respondents allow to be shown. It may be that they did not wish to reveal particular issues affecting referral decision making, especially if they felt these to be discriminatory and therefore possibly negatively
perceived. It is argued that the ‘self-serving attributional bias’ is pervasive, with people having a strong need to seek a positive image of themselves (Mezulis et al., 2004). People are likely to feel that discriminatory behaviour may be negatively perceived, and thus be unlikely to reveal such influences on referral practice. However, it is suggested that the ‘form of rhetoric’ within an interview does give shape to claims of the way that people work (Armstrong, 2002), and so any biases may emerge in a tempered form. There was no evidence of any such biases in any interviews or observations.

Another explanation is that the apparent inequities in access are in fact related to differences in need, and that whilst there may be the barriers to referral documented in this research they are not systematically inequitable. Certainly there are methodological problems with much of the research reviewed because it looks at utilisation or realised access without information on the causes of any inequities found. The literature revealing the apparent inequality in access for those who are older has been particularly criticised in this regard for only looking at use, not clinical need (Burt and Raine, 2006). It may be that differences in service use purely reflect differences in clinical need for services, or a difference in how needs for services are perceived by health care professionals. The data in this research appear to lend more support for this explanation. Whilst no estimation of clinical need was made within this study, respondents did report that their assessments of needs of patients differed. For example they perceived the needs of younger patients to be greater than their own resources were capable of meeting, thus triggering referral. Respondents also reported that the needs of those from some ethnic minority communities were felt to be different because of the family and community support they might receive. The causes of such differences in service use patterns are likely to be multi-faceted and complex, rather than any single factor. However, research reported in this thesis suggests that one possible cause of apparent inequities in access may be related to differences in the way professionals perceived the needs and resources of different patients, and their own resources to meet these needs.
9.5 Critique of research

This section considers the strengths and limitations of the research reported here and the impact of the chosen research strategy.

Limitations

This study is partly limited by its size, particularly the amount and type of data collected. Whilst a large volume and depth of data were collected, a larger study could have tested the theoretical propositions across different cases, and used additional data collection methods. This limitation is perhaps inevitable in a study conducted in fulfilment of an academic qualification, where there are constraints of time and only a single researcher conducting the research. There are however particular limitations to the data collected and these are explored further: issues of recruitment, issues of data deliberately excluded from the study, and issues with the method.

Fewer patient respondents were recruited than initially envisaged. The reason for this seemed to be the reluctance of health care professionals to recruit patients rather than patients declining to take part in the study. This particular form of recruitment via the patients’ own healthcare professional was requested by the research ethics committees, and seen generally as good practice at the time for reasons of data protection and research governance. However, it is increasingly recognised that this form of practitioner control of sample selection can severely affect recruitment, and hence the validity of the sample (Ewing et al., 2004). Ewing et al. (2004) suggest that the practitioner barriers to recruitment in their study were pressures of work and a protective attitude towards patients. Informal contact with health care professionals in this study suggested that these were also recruitment obstacles. These recruitment issues impacted on the way patient data was used to support the findings and theoretical propositions of the study. The patient ‘voice’ within the study is less than it could have been, and their views on referral decisions harder to discern.

Another participant group from whom it proved hard to recruit were general practitioners. Whilst general practitioners were recruited into the study in the
numbers initially envisaged this was only after significantly more invitations to participate had been issued than initially expected. As reported in chapter 4, whilst nearly all specialist palliative care professionals invited to participate in the study did so, and nearly 41% of district nurses, only 15% of general practitioners did so. In addition, those general practitioners who did participate generally only did so after more efforts were made to contact them directly and discuss the study with them. Most cited workload as a barrier to participation, and it may be that only those with a particular interest in palliative care and the study took part. It is noted earlier that all respondents appeared committed to palliative care provision, but it is not possible to know whether the opinions of those recruited differed to those who did not participate. Too few general practitioners were recruited to make any meaningful comparisons of their characteristics (age, length of qualifying etc.) with any national or local datasets.

Decisions were also made early in the study not to actively recruit carers or social care professionals. In the case of social care professionals, the rationale was to limit the scope of the study to health care practices. There were pragmatic reasons for this, recognising the limited amount of time and resource available for the study as it is known that few social care professionals refer to specialist palliative care services (Costantini et al., 1999; Kite et al., 1999; Skilbeck et al., 2002). Recruitment of social care professionals was possible due to the snowball sampling technique when respondents were asked to suggest people to interview, and one specialist palliative care social worker was interviewed; however no other social care professionals were suggested. It is possible that the reasons given for referral of palliative care patients to and from social care professionals may be very different, recognising the often subtle and difficult divisions between health and social care, and the very different perceptions of each others roles (Griffiths, 1998; Bliss, 1998). Some of the data do point to issues for social care professionals, for example their role at the very end of life, and these issues may be worth pursuing further.

Carers may have their own views on referrals based on both their own needs as carers and their interpretation of patients’ needs (Payne et al., 1999; Jarrett et al., 1999b; Beaver et al., 1999c; Brobäck and Berterö, 2003; Hudson, 2004; Cain et al., 2004; Stajduhar and Davies, 2005; Appelin et al., 2005), but in this study a
choice was made to focus on patients’ views. Carers were not actively recruited because a decision was made to directly recruit patients to the study to elicit their views. Carers (often bereaved carers) have often been recruited to palliative care studies as a proxy for patients, usually in recognition of the difficulty of recruiting patients in the palliative phase of illness. However, questions have been asked about the validity of their responses (Higginson et al., 1994; Nekolaichuk et al., 1999), which influenced the decision made to recruit patients directly.

Few opportunities to collect observational data were also identified. Whilst this is partly because few respondents suggested relevant opportunities, some meetings identified by respondents were not observed. This was due to a combination of factors; cancelled meetings, infrequent meetings, and reluctance on the part of some meeting participants for me to attend and observe. The observational data collected is an interesting counterpoint to the interview data, revealing different patterns of interaction between professionals to that anticipated from the interview data, and could have contributed more to the overall picture if more data had been collected.

The focus of the study on referrals within community palliative care services also means that the views of those who referred from outside such services were not considered. Whilst this is a different research question and study, its omission needs to be noted as some referrals to community palliative care services originate from other, primarily hospital based, sources (Skilbeck et al., 2002).

Difficulties in obtaining what were anticipated to be routinely available data were also experienced. It had been anticipated that it would be possible to obtain current and historical data from services, particularly specialist services, within the cases about referral patterns: numbers of patients referred, source of referral, age of those referred, diagnosis and ethnic origin. However this data was only obtained for one service. Whilst all the district nursing services collected this data routinely, it proved impossible for the relevant information departments to disaggregate meaningful information about just patients in the palliative phase of their illness, or even with a diagnosis which may be assumed to be palliative. In the absence of specialist staff in case study A, the information department were reluctant to release this information. Other data was not released by the staff or departments
concerned. In retrospect, and with more resources, it may have been preferable to collect this data prospectively, perhaps also collecting data about reasons for referral given.

A further limitation of this study, as with most research studies, is that the findings are inevitably temporally and geographically bound. The field work was conducted at a particular moment in time, in particular places, and with particular influences on the data created at that time. Current issues which appeared to influence respondents included the implementation of the new general practitioner contract, recent investment in palliative care education for district nurses, the NICE supportive and palliative care guidance, and the promulgation of the Gold Standards Framework and Liverpool Care Pathway for the dying.

The analysis in this study is inevitably a personal analysis. Whilst much attention has been paid to making the analysis and interpretation of data as transparent and rigorous as possible it was hard to completely put aside my own history of working within community palliative care settings. It can be argued that any case study is a construction – a product of the interaction between respondents, site and researcher. This construction is therefore rooted in the person, character, experience, context and philosophy of the constructor (Lincoln and Guba, 2002). Considerable care was taken to attempt to view what could be familiar settings in a questioning way. Some of the respondents were also aware of my background, as I was honest if asked about my past professional experiences. This may have affected the way they spoke to me, and did cause some consternation when they perceived that I asked questions to which they judged I may already know the answer. It is hoped that this awareness of the influence I could have on the study, the use of theoretical propositions which partly reflected past experiences, together with the steps taken to ensure rigour, have ensured the construction of a case study which withstands scrutiny.

Strengths

The collection of data from multiple sources is a particular strength of this work. Many of the studies reviewed in chapter 2 are essentially uni-professional, and make recommendations based on the views of one professional group. Most
studies also only look at one particular way of providing specialist palliative care. However, community palliative care is provided by a range of general and specialist professionals and services, and it has proved important to capture the interrelationships between these. Only a study which took account of these different perspectives could have revealed such inter-relationships. The multiple methods of data collection are also a strength of the study. Seeking multiple perspectives on the same phenomenon allowed complexities of referral practices to be more readily revealed than might have been possible.

The study also gains from being a cross case analysis of practices considered first in context. The cases studied provided specialist palliative care in very different ways, each with particular strengths and weaknesses. However, the cross case analysis revealed that similar underlying issues affected referral decision making. The cases were based on a theoretical replication – the supposition being that referral practices would differ with the different contexts. Whilst referrals are to some extent context driven, for example by the availability of services, the influences on referrals crossed contexts and forced the theoretical propositions to be re-visited. The strength of this design is that those in very different contexts to those studied may find utility in the findings because of the theoretical generalisability of the findings.

The study also gained from the flexible nature of the design. Some of the responses of those taking part were not anticipated at the start of the study, for example the influence of the frequent negative judgements professionals made about each other on referrals. The iterative nature of the design meant that the interview topic guide could be amended to explore this and other issues raised in more depth.

The study was also conducted in a rigorous way, with care taken at all stages of the research to pay attention to best practice. All the procedures outlined in section 4.9 were followed. However, were this study to be replicated, different choices could be made which would further strengthen the research. A larger study could incorporate the views of those excluded from the study, principally carers, social care professionals, and those referring from outside community palliative care services. More cases could be studied, to further test the theoretical
propositions, and more data collected from different sources, for example, observational data and prospective referral data from services and individuals studied.

In summary, whilst recognising the limitations of the research, this study essentially achieved most of its objectives. The issues of how and why professionals working within community palliative care services made referrals and the influences on those processes are described and presented here. A case study strategy appears appropriate to describe these issues. A particular strength of the design is the cross-case analyses which revealed the fundamental nature of the influences on referral practices despite the different contexts of the primary care trusts studied. This study was also inevitably a learning process, with choices made, particularly about data collection processes, which could have been improved upon. However, essentially, the design of the study, and the rigour with which it was conducted was sufficient to produce justifiable and compelling findings which should have utility and resonance with practitioners, policy makers and fellow researchers.

9.6 Recommendations for future research

There are questions arising from this study which could be addressed with future research. These are briefly explored below.

Research is needed which explores further any possible relationship between the personal, professional and inter-professional influences on referral practices described within this thesis and the evidence of apparent inequities in referral to and utilisation of palliative care services. Such research could explore more fully the way that the different clinical needs of patients’ impact on both utilisation of services and the decisions made by professionals as one possible explanation, or also explore decisions made for inherent biases not revealed by this current research.

The relationship between clinical needs of patients (and their carers) and referrals made is also an issue which merits further exploration. There is an implicit assumption in the research presented in chapter 2 of equal need amongst patients
with different characteristics. In addition, equity of need is not the same as equity of treatment or equality of outcomes. This can cause significant difficulty in research, as need is more difficult to define and study, and most research looks at access to or the utilisation of treatment, or the relationship between access and outcome. Ways of usefully studying clinical need could be explored.

Further research is also needed into the influences on referral practice outside community palliative care services. The rationale for the choices of others referring into community palliative care services could be explored (for example social care professionals, or those working in in-patient settings), as well as how and why referrals are made within hospital based palliative care services.

A further area from this research which could be explored is the tacit acceptance by professionals of variance in practice, including variance they believe to be sub-standard. Research which helps understanding of why professionals choose not to challenge the work of others could facilitate devising effective methods of improving practice.

In addition, the contribution of generalists to the provision and outcomes of palliative care warrants further exploration. This research has demonstrated the importance generalists place on their own contribution to palliative care, yet most research only investigates the outcomes of specialist palliative care. Research needs to recognise the complexity of care provision, exploring the outcomes of care for patients seen only by generalists, and those receiving different forms of specialist care. Such work would also need to be related to patient need.

9.7 Recommendations for policy, practice and education

Recommendations for policy, practice and education have been made throughout the previous sections. For clarity, they are re-iterated here.

- Policies and protocols need to take account of the complex and subtle influences on referrals, rather than simply mandating practice changes. Their implementation should be considered, with best practice in using multiple methods to disseminate and implement policy followed.
• Local referral policies should be explicitly stated, with detailed information to guide practice. Exceptions to following such policies should be documented.
• Partnership may be helpful only when there is a clear rationale, or explicit benefit with minimal costs.
• Professionals could be more explicit about their referral behaviours, justifying to themselves, other professionals and patients why particular choices have been made.
• Actions to promote teamwork may promote referrals. Sharing working space or bases, shared documentation and spending social time together may have an impact on referral practices.
• Education may be a potent way of changing referral practices, and both early inter-professional education and continued joint educational opportunities may facilitate referrals.

9.8 The contribution of the thesis

The central contribution of this thesis is in exploring access within community palliative care services and uncovering personal, professional and inter-professional influences on referral decisions professionals made. Most prior research investigating access to community palliative care services has essentially looked at the outcomes of referral processes – which patients are actually referred – not the processes impacting on referral practices. Whilst many of the influences on the way professionals behave in practice have already been described in the research of others, relating such behaviour explicitly to referral practices in palliative care is new.

Commonly, studies investigating outcomes of referrals have been retrospective reviews of routinely collected structured data. The questions guiding these studies typically address hypothesised relationships between service utilisation and specific patient-related variables such as patient age, gender, and diagnosis. There is often little discussion of why the variables of interest have been chosen, although it can be supposed from some of the papers that the choice was influenced by prior research and the ready availability of such data from patient, carer or other records. Such studies suggest bias in referrals towards, for
example, patients who are younger, with particular cancers, who already have social support at home, or who are from particular ethnic backgrounds. These studies go on to suggest future research based on findings related to age or referral biases (Addington-Hall and Altmann, 2000; Grande et al., 2002; Hagen et al., 2006) research which would continue to add depth of knowledge to this field.

However, what such work does not do is add breadth to this field. By focusing on a defined series of patient-related variables, using a narrow range of research techniques, such studies perpetuate attention on these variables to the exclusion of others, presupposing that we know which variables are of relevance. However, these variables are not always found to be explanatory when investigated further. For example a study hypothesising that the reason age influenced access was because of older peoples attitudes towards referral found that this was not the case (Catt et al., 2005). What the research reported in this thesis does is take an open, flexible and iterative approach to this subject, discovering that patient characteristics appear less important to the professionals making the referral decisions than their views on their own and others’ roles in practice.

There has been some attention paid to some of these influences, identified in the literature reviewed in section 2.3.5. Some similar issues were identified in this section: the impact of knowing about services, the influence of positive attitudes about palliative care; the feeling that general palliative care may be sufficient; and perceptions of patients’ feelings about referrals. However generally the studies contributing to this emerging knowledge were either small in scale, only tangentially investigated these aspects, or focused only on one element of such influences, generally within one professional group. This study is innovative in exploring many influences on referral practices, in a flexible fashion facilitating new discoveries, and involving many different general and specialist palliative care professionals.

The key issue is that different approaches to the same topic can yield different insights. To date, similar questions have been addressed using similar methods, producing similar findings. The research reported here has shown the potential of other methods to raise new sets of questions, and identify previously unanticipated reasons for the referral patterns demonstrated by the research of others.
This research also casts light on how policies operate in practice. An example is the Gold Standards Framework, designed to promote a more equitable and standard approach to palliative care in the community, facilitating early awareness of palliative care patients. However, whilst this research does not pretend to study this policy, the referral responses of those working within the framework appear to show that for some professionals the converse can be true, and that their work with patients is delayed. This research therefore has important implications for policy makers, who need to take account of these personal, professional and inter-professional factors on both the formulation and operation of policy.

Furthermore, studying referral practices seems to illuminate professional working practices more generally. Referral practices can be seen as a ‘way in’ to understanding more universal issues within community palliative care services, and the wider healthcare community. Issues such as autonomy, patient ownership and the judgement of other professionals may be particularly highlighted in palliative care because of its ‘status’, but are also likely to be important in ongoing encounters between healthcare professionals.

9.9 Conclusions

This research demonstrates that understanding referral processes is a key prerequisite to understanding patterns of service utilisation. Referrals have been found to be predicated as much on the assessments of those making and receiving referrals about their own and others capacities as professional carers as on the clinical needs of patients. Such assessments affect which patients are chosen to receive specialist palliative care, which may then have a bearing on outcomes. The professionals in this study did not appear to believe that such influences on decisions affected their abilities to provide equitable care, as every patient was subject to the same process of consideration regarding the roles of others who could be involved in their care.

This study has illuminated how such appraisals of self and others affect referral practices. The implications of this study for policy and practice have been identified and recommendations made for further research. In particular, this study
raises questions about the relationship between equity of access, clinical need, and professional issues affecting referral practice.
References


Addington-Hall J., Altmann D. & McCarthy M. (1998a) Variations by age in symptoms and dependency levels experienced by people in the last year of life, as reported by surviving family, friends and officials. *Age and Ageing* 27, 129-137.


Popay J., Rogers A. & Williams G. (1998) Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research* **8**, 341-351.


Read S., Ashman M., Scott C. & Savage J. (2004) *Evaluation of the modern matron role in a sample of NHS trusts*. The Royal College of Nursing Institute and the University of Sheffield School of Nursing and Midwifery, Sheffield and London.


Appendix One – Example of literature review search strategy

Search strategy used to search Medline.

<table>
<thead>
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<th>#</th>
<th>Search History</th>
<th>Results</th>
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<tr>
<td>1</td>
<td>terminal.mp. or exp Terminal Care/</td>
<td>246652</td>
</tr>
<tr>
<td>2</td>
<td>exp Palliative Care/ or palliat$.mp. or exp Hospices/</td>
<td>40951</td>
</tr>
<tr>
<td>3</td>
<td>hospic$.mp.</td>
<td>6811</td>
</tr>
<tr>
<td>4</td>
<td>end of life.mp.</td>
<td>3903</td>
</tr>
<tr>
<td>5</td>
<td>terminally ill.mp. or exp Terminally Ill/</td>
<td>5617</td>
</tr>
<tr>
<td>6</td>
<td>specialist palliative care.mp.</td>
<td>197</td>
</tr>
<tr>
<td>7</td>
<td>access.mp.</td>
<td>74279</td>
</tr>
<tr>
<td>8</td>
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</tr>
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<td>barrie$.mp.</td>
<td>74488</td>
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<tr>
<td>10</td>
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<tr>
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<td>1500</td>
</tr>
<tr>
<td>13</td>
<td>gatekeeping.mp. or exp Gatekeeping/</td>
<td>501</td>
</tr>
<tr>
<td>14</td>
<td>allocation.mp. or Resource Allocation/</td>
<td>72326</td>
</tr>
<tr>
<td>15</td>
<td>assessment.mp. or exp &quot;Outcome and Process Assessment (Health Care)=&quot;/ or exp Needs Assessment/ or exp Geriatric Assessment/ or exp &quot;Process Assessment (Health Care)=&quot;/ or exp Nursing Assessment/ or exp &quot;Outcome Assessment (Health Care)=&quot;/</td>
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<tr>
<td>17</td>
<td>exp &quot;Health Services Needs and Demand&quot;/</td>
<td>25727</td>
</tr>
<tr>
<td>18</td>
<td>obstacle$.mp.</td>
<td>11507</td>
</tr>
<tr>
<td>19</td>
<td>exp Socioeconomic Factors/ or exp Social Class/ or inequity.mp. or exp Social Justice/</td>
<td>218345</td>
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<td>4427</td>
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<td>620074</td>
</tr>
<tr>
<td>32</td>
<td>29 and 30 and 31</td>
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</tr>
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<td>33</td>
<td>limit 32 to (humans and &quot;all adult (19 plus years)&quot;)</td>
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Appendix Two – Table of contents alerts for the literature review

Table of contents alerts were in place during the study for the following journals. This is the maximum number allowed by the ZETOC alerting service, and were chosen as the journals most likely (from the initial literature search) to have articles relevant to the study.

Appendix Three – Research quality scoring system

1 Abstract and title: Did they provide a clear description of the study?

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
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<tbody>
<tr>
<td>Good</td>
<td>Structured abstract with full information and clear title</td>
</tr>
<tr>
<td>Fair</td>
<td>Abstract with most of the information</td>
</tr>
<tr>
<td>Poor</td>
<td>Inadequate abstract</td>
</tr>
<tr>
<td>Very poor</td>
<td>No abstract</td>
</tr>
</tbody>
</table>

2 Introduction and aims: Was there a good background and clear statement of the aims?

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Full but concise background to discussion/study containing up to date literature review and highlighting gaps in knowledge</td>
</tr>
<tr>
<td>Fair</td>
<td>Some background and literature review. Research questions outlined</td>
</tr>
<tr>
<td>Poor</td>
<td>Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background</td>
</tr>
<tr>
<td>Very poor</td>
<td>No mention of aims/objectives. No background or literature review</td>
</tr>
</tbody>
</table>

3 Method and data: Is the method appropriate and clearly explained?

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Method is appropriate and described clearly (e.g. questionnaires included). Clear details of the data collection and recording.</td>
</tr>
<tr>
<td>Fair</td>
<td>Method appropriate, description could be better. Data described.</td>
</tr>
<tr>
<td>Poor</td>
<td>Questionable whether method is appropriate. Method described inadequately. Little description of data.</td>
</tr>
<tr>
<td>Very poor</td>
<td>No mention of method, AND/OR Method inappropriate, AND/OR No details of data</td>
</tr>
</tbody>
</table>

4 Sampling: Was the sampling strategy appropriate to address the aims?

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and justified.</td>
</tr>
<tr>
<td>Fair</td>
<td>Sample size justified. Most information given, but some missing.</td>
</tr>
<tr>
<td>Poor</td>
<td>Sampling mentioned, but few descriptive details</td>
</tr>
<tr>
<td>Very poor</td>
<td>No details of sample.</td>
</tr>
</tbody>
</table>

5 Data analysis: Was the description of the data analysis sufficiently rigorous?

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Clear description of how analysis was done. Qualitative studies: description of how themes derived/respondent validation or triangulation. Quantitative studies: Reasons for selected hypothesis driven /numbers add up/ statistical significance discussed.</td>
</tr>
<tr>
<td>Fair</td>
<td>Descriptive discussion of analysis.</td>
</tr>
<tr>
<td>Poor</td>
<td>Minimal details about analysis.</td>
</tr>
<tr>
<td>Very poor</td>
<td>No discussion of analysis.</td>
</tr>
</tbody>
</table>
6 **Ethics and bias:** Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

**Good**

Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed.

Bias: Researcher was reflexive and/or aware of own bias.

**Fair**

Lip service was paid to above (i.e. these issues were acknowledged)

**Poor**

Brief mention of issues.

**Very poor**

No mention of issues.

7 **Results:** Is there a clear statement of the findings?

**Good**

Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.

**Fair**

Findings mentioned but more explanation could be given. Data presented relate directly to results.

**Poor**

Findings presented haphazardly, not explained, and do not progress logically from results.

**Very poor**

Findings not mentioned or do not relate to aims.

8 **Transferability or generalisability:** Are the findings of the study transferable (generalisable) to a wider population?

**Good**

Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in question 4 (sampling)

**Fair**

Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.

**Poor**

Minimal description of context/setting

**Very poor**

No description of context/setting.

9 **Implications and usefulness:** How important are these findings to policy and practice?

**Good**

Contributes something new and/or different in terms of understanding/insight or perspective.

Suggests ideas for further research.

Suggests implications for policy and/or practice.

**Fair**

Two of the above (state what is missing in comments)

**Poor**

Only one of the above.

**Very poor**

None of the above.

From Hawker et al (2002)

Good = 4, Fair = 3, Poor = 2, Very poor = 1.
Appendix four – Letter of invitation to professional respondents

Dear (health care professional’s name),

Re: Community palliative care; investigating referral decisions

I am writing to ask if you would kindly take part in this research study. The purpose of the study is to investigate how and why health care professionals providing community palliative care services make decisions about referring and caring for their patients. Research indicates that patient, professional and organisational factors all probably play a part in making these decisions. This research aims to investigate these factors. I very much want to talk to a wide range of professionals and managers, and hope that you could spare about half an hour to an hour of your time to speak to me.

Research ethics committee approval for the study has been obtained. The study has also received approval from (insert details). The researcher also holds an honorary contract with the PCT. I have attached some more detailed information about the study for you to read and consider.

I am sure that you will wish to take time to consider the project before deciding whether or not to become involved. A reply slip and stamped addressed envelope is enclosed for your reply, but if I don’t hear from you I hope you will not mind me ringing to discuss the study with you.

Yours sincerely,

Catherine Walshe
Nurse Researcher
A study of referral in community health care services

Please tick (✓) as appropriate:

I am willing to be contacted about taking part in this research study

I am not willing to be contacted about taking part in this research

Name .................................................................

Address .................................................................

.................................................................

.................................................................

.................................................................

Telephone Number .................................................................

E-mail address .................................................................

Date ........................................................................

Please indicate the best times for me to contact you, if you are willing to take part in this research

........................................................................

........................................................................

Thank you for your help, please return the enclosed form in the stamped addressed envelope provided and return to:

Catherine Walshe, Nurse Researcher, School of Nursing, Midwifery and Social Work, University of Manchester, Coupland III, Oxford Road, Manchester, M13 9PL. Telephone 0161 275 8700.
Appendix six – Information sheet for professional respondents

Community health care services; investigating referral decisions

(Version 3, May 2003)

You are being invited to take part in a research study looking at how and why patients are referred to community health care services. The study plans to include services such as district nursing, specialist nurses, day care, general practitioners etc. Before you decide whether to take part, I would like you to understand more about why the research is being done and what it will involve. Please take time to read the following information carefully. Ask me if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

What is the purpose of the study?
Community health care services are very important in providing high quality care to patients. However, we don’t understand much about how health care professionals make decisions about who to provide care to, and how different services work together. We do know that there can be confusion about what different services are offering patients. This study aims to look at how and why referral decisions are made within your local area. The study will be taking place in three different Primary Care Trusts over the next two years.

Why have I been chosen?
You have been chosen because you provide community health care within the (insert name) Primary Care Trust area. The Primary Care Trust has agreed that the study can take place here, but obviously it is up to you whether you personally participate in the research. Ethics approval for this study has been granted from (insert name) Research Ethics Committee.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without prejudice and without giving a reason.

What is involved in taking part?
Because this study is taking a case study approach to the research, different research methods are being used to address various aspects of the same study. Your participation in the research may therefore involve some or all of the following.

Observation. If you are involved in regular meetings to discuss the assessment and referral of patients I would like to observe one of these meetings.

Interview. I will interview you once about your approach to referring patients. This will be at a time and place of your choosing. This interview will probably last for between 30 minutes and an hour. If you agree, the interview will be tape-recorded. All the notes and/or tape recordings that may have been made will be securely stored and destroyed after a period of time.
**Identifying patients.** As part of the study, I also plan to interview some patients. I would like the initial approach to them to come from you. If possible, therefore, I would like you to identify one patient whom you think would be willing and able to participate in this research. Ethics approval for this has been obtained. Informed consent from the patient would be sought before the interview, and I have appended a copy of the information sheet I would be sending to patients before they were interviewed.

**What are the possible risks and benefits of taking part?**
There should be no risks to you in taking part in this study. We hope that the information from this study will help us all to provide better community health care services in the future.

**What if something goes wrong?**
It is unlikely that you will come to any harm by taking part in this study. However, if you are unhappy with any aspect of the way that you are treated, you should inform either your manager or the researcher. You may also make a complaint to the project advisory group. Any complaint that you might make will be taken very seriously. In order to protect you further, the project will be covered by the University of Manchester's insurance for research studies.

**Will my taking part in this study be kept confidential?**
All information that is collected about you or your patients during the course of the research will be kept strictly confidential. Any information stored about you (such as notes from the interview) will have your name and contact details removed so that you cannot be recognised from it. Any details reported in research reports or other publications will have any information that could identify individuals removed or altered. Any published reports will not name the Primary Care Trusts where the research took place, but will refer to them in terms of their features i.e. geography, demography. Data collected in this study will be subject to analysis in accordance with the registration of the University of Manchester under the Data Protection Act 1998.

**What will happen to the results of the research study?**
The research study results will be written up as part of a thesis for a higher degree, and will be disseminated more widely through articles in academic and professional journals. A short, anonymised, summary with key findings will be circulated to all those who participated in the research.

**Who is organising and funding the research?**
This research is being undertaken by the School of Nursing, Midwifery and Social Work at the University of Manchester. The researcher is funded by an award from the Department of Health.

**Who has reviewed the study?**
The study has been reviewed by the (insert name) Local Research Ethics Committee. It was also reviewed by experts in research from the Department of Health to assess whether it was worthy of funding.

**Contacts for further information.**
Thank you for taking the time to read and consider this information. Please feel free to discuss it with others before deciding whether or not to take part. If you have any further queries, please do not hesitate to ask. You can contact the nurse researcher directly as follows:

Catherine Walshe  
The School of Nursing, Midwifery and Social Work  
University of Manchester  
Coupland III  
Oxford Road  
Manchester  
M13 9LP

Tel: 0161 275 8700  
e-mail: catherine.walshe@manchester.ac.uk

If you would like independent advice about the study before deciding whether or not to take part, you can speak with a member of the study’s advisory group, who can be contacted as follows.

Dr Bernadette Ryan Woolley  
The School of Nursing, Midwifery and Social Work  
Gateway House  
Piccadilly South  
Manchester

Tel: 0161 237 2159

We would be very grateful if you would complete the enclosed reply slip – whether you decide to take part in the study or not – and return it to us in the stamped addressed envelope enclosed

Thank you.
Dear (key informants name),

Re: Community palliative care; investigating referral decisions

I am writing to ask if you would kindly take part in this research study. The purpose of the study is to investigate how and why health care professionals providing community palliative care services make decisions about referring and caring for their patients. Research indicates that patient, professional and organisational factors all probably play a part in making these decisions. This research aims to investigate these factors. I very much want to talk to a wide range of professionals and managers, and hope that you could spare about half an hour to an hour of your time to speak to me. Data will be collected within each case from a number of sources that includes interviewing key informants within the Primary Care Trust about the planning, commissioning and management of community palliative care services.

Research ethics committee approval for the study has been obtained. The study has also received approval from (insert details). The researcher also holds an honorary contract with the PCT. I have attached some more detailed information about the study for you to read and consider.

I am sure that you will wish to take time to consider the project before deciding whether or not to become involved. A reply slip and stamped addressed envelope is enclosed for your reply, but if I don’t hear from you I hope you will not mind me ringing to discuss the study with you.

Yours sincerely,

Catherine Walshe
Nurse Researcher
Appendix eight – Information sheet for non health care professional respondents

Key Informants information sheet
(version 2, March 2003)

Community health care services; investigating referral decisions

You are being invited to take part in a research study looking at how and why patients are referred to community health care services. Whilst the study plans to look at services such as district nursing, specialist nurses, day care, general practitioners etc., we are also interested in the views of those who manage, commission or plan services. Before you decide whether to take part, I would like you to understand more about why the research is being done and what it will involve. Please take time to read the following information carefully. Ask me if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

What is the purpose of the study?
Community health care services are very important in providing high quality care to patients. However, we don’t understand much about how health care professionals make decisions about who to provide care to, and how different services work together. Existing research also doesn’t tell us much about whether the care offered meets the expectations of patients. We do know that patient’s needs are not always met, and that there can be confusion about what different services are offering patients. This study aims to look at how and why referral and assessment decisions are made within your local area. The study will be taking place in three different Primary Care Trusts over the next two years.

Why have I been chosen?
You have been chosen because you manage, commission or plan community health care within this Primary Care Trust area. The Primary Care Trust (and or other voluntary organisations) have agreed that the study can take place here, but obviously it is up to you whether you personally participate in the research. Ethical approval for this study has been granted from the (name) local research ethics committee.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without prejudice and without giving a reason.

What is involved in taking part?

Interview. I will interview you once about your views on community health care services. This will be at a time and place of your choosing. This interview will probably last for between 30 minutes and an hour. If you agree, the interview will be tape-recorded.
**Identifying appropriate documents.** At your interview, I will also ask you to identify any documents which I could look at which refer to the commissioning, planning or management of community health services.

**What are the possible risks and benefits of taking part?**
There should be no risks to you in taking part in this study. We hope that the information from this study will help us all to provide better community health care services in the future.

**What if something goes wrong?**
It is unlikely that you will come to any harm by taking part in this study. However, if you are unhappy with any aspect of the way that you are treated, you should inform either your manager or the researcher. You may also make a complaint to the project advisory group. Any complaint that you might make will be taken very seriously. In order to protect you further, the project will be covered by the University of Manchester’s insurance for research studies.

**Will my taking part in this study be kept confidential?**
All information that is collected about you during the course of the research will be kept strictly confidential. Any information stored about you (such as notes from the interview) will have your name and contact details removed so that you cannot be recognised from it. Any details reported in research reports or other publications will have any information that could identify individuals removed or altered. Any published reports will not name the Primary Care Trusts where the research took place, but will refer to them in terms of their features i.e. geography, demography. Data collected in this study will be subject to analysis in accordance with the registration of the University of Manchester under the Data Protection Act 1998.

**What will happen to the results of the research study?**
The research study results will be written up as part of a thesis for a higher degree, and will then be disseminated more widely through articles in academic and professional journals. A short, anonymised, summary with key findings will be circulated to all those who participated in the research.

**Who is organising and funding the research?**
This research is being undertaken by the School of Nursing, Midwifery and Social Work at the University of Manchester. The researcher is funded by an award from the Department of Health.

**Who has reviewed the study?**
The study has been reviewed by the (name) Local Research Ethics Committees. It was also reviewed by experts in research from the Department of Health to assess whether it was worthy of funding.

**Contacts for further information.**
Thank you for taking the time to read and consider this information. Please feel free to discuss it with others before deciding whether or not to take part. If you have any further queries, please do not hesitate to ask. You can contact the research nurse directly as follows:

Catherine Walshe
If you would like independent advice about the study before deciding whether or not to take part, you can speak with a member of the study’s advisory group, who can be contacted as follows.

Dr Bernadette Ryan Woolley
The School of Nursing, Midwifery and Social Work
Gateway House
Piccadilly South
Manchester

Tel: 0161 237 2159

We would be very grateful if you would complete the enclosed reply slip – whether you decide to take part in the study or not – and return it to us in the stamped addressed envelope enclosed.

Thank you.
Appendix nine – Consent form for professional respondents

CONSENT FORM

Title of Project: Community health care services: investigating referral decisions

Name of Researcher: Catherine Walshe

1. I confirm that I have read and understand the information sheet dated May 2003 (version 3) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my rights being affected.

3. I give permission for the interview which I give to be recorded. I understand that this recording will be securely stored, and destroyed after a period of time.

4. I agree to take part in the above study.

Name of Participant Signature Date

Name of Person taking consent (if different from researcher) Signature Date

Researcher Signature Date

1 for participant; 1 for researcher
Appendix ten – Information for health care professional about recruiting patients for the study

Dear,

This is the information I’d like you to share with patients. As part of the research process I would like you to identify a patient of yours for me to speak to. I’ve enclosed two packs of information for you to give to patients. I’m not expecting you to recruit more than one patient, but thought it might be useful to you to either have a copy for your own records, or to recruit a further patient should the first one not wish to participate.

Each patient should receive a letter from you, an information sheet about the study, a reply slip and a stamped addressed envelope. I have enclosed a stamped envelope, should you wish to post the information to patients. The patients with whom you discuss the study should meet the inclusion criteria for the study, which I have specified below:

Patients will be eligible for inclusion if they are:

- Adults (age 18+, no upper age limit)
- Assessed by their health care professional as being in the palliative phase of their illness.
- Assessed by their health care professional as being able to understand and consent to participation in the research.
- Aware of their diagnosis and prognosis
- Referred to a service providing community palliative care for residents of (name) PCT.

There will be an equal opportunity to participate in the research regardless of gender, disability, ethnicity or language spoken. Please let me know if any patient requires any particular additional resources they may need to participate i.e. native language speakers, translations of information sheets, escorts etc.

Please feel free to speak to any patient about the study, and to give them the information enclosed. I am particularly interested in speaking to patients who have recently been referred to your service or by you to another service. However, if you do not have such patients on your caseload, I can talk to any patient who meets the inclusion criteria above.

Thanks very much for your help with the study. I will probably contact you before speaking to any patients, to check that they are currently well and possibly to arrange to meet them during one of your routine visits, with your permission.

I look forward to talking with you again.
Yours sincerely

Catherine Walshe
Department of Health Research Training Fellow
Appendix eleven – Letter of invitation to patients

Dear

Re: A study of referral in community health care services

I am writing to invite you to take part in some research that is being carried out with patients receiving community health care services. (name) Primary Care Trust is working with a nurse researcher at the University of Manchester on this study.

The aim of the study is to find out more about how and why patients are referred to community health care services, so that we can understand more about how to provide services in the best possible way. We are interested in what you expected from any community services you have been referred to, and whether your expectations have been met. Participation is entirely voluntary, and your care will not be affected in any way if you choose not to take part in this research.

I have attached some information, which I hope you will find helpful in deciding whether or not to take part in the study. Contact details are given on the attached information sheet should you have any questions. Enclosed with this letter are a return slip and pre-paid envelope for you to send back to the nurse researcher with your decision. I would be grateful if you would complete and return the reply slip, even if you decide not to take part in the study. Thank you for taking the time to read and consider this invitation.

Yours sincerely,

(name of health care professional)
Appendix twelve – Response sheet from patients

A study of referral in community health care services

Please tick (✓) as appropriate:

I am willing to be contacted about taking part in this research study

I am not willing to be contacted about taking part in this research

Name ……………………………………………………………

Address ……………………………………………………………

…………………………………………………………

…………………………………………………………

…………………………………………………………

…………………………………………………………

Telephone Number ……………………………………………………………

Name of health care professional who gave you this form

……………………………………………………………………………

Please tick (✓) as appropriate:

I can be contacted by telephone to arrange a suitable time for you to call

I cannot be contacted by telephone, please call on one of the following days (please indicate time and date)

……………………………………………………………………………

Thank you for your help, please return the enclosed form in the stamped addressed envelope provided and return to: Catherine Walshe, Nurse Researcher, School of Nursing, Midwifery and Social Work, University of Manchester, Coupland III, Oxford Road, Manchester, M13 9PL. Telephone 0161 275 8700.

Please return in the envelope provided
Appendix thirteen – Information sheet for patients

Patient information sheet
(version 3, May 2003)

Community health care services; investigating referral decisions

You are being invited to take part in a research study looking at how and why patients are referred to community health care services. This may include a range of services such as a district nurse, General Practitioner, specialist nurse or day care facility. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

What is the purpose of the study?
Community health care services are very important in providing high quality care to patients. However, we don’t understand much about how people providing this care make decisions about what care to provide. We also don’t know whether the care that they offer meets the needs and expectations of patients. We do know that sometimes there is confusion about what different services are offering patients. This study aims to look at how and why these referral decisions are made within your local area. The study will be taking place in different areas over the next two years, but you will only be interviewed once.

Why have I been chosen?
You have been chosen because someone who provides community health care in your local area is currently seeing you, or you have just been referred to them. This may be your GP, district nurse, specialist nurse, day care facility or someone else involved in your health care. We hope to talk to about 10 or 15 patients in each area. We will also be talking to doctors, nurses and other health care workers in the area about their views on community health care services.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
The nurse researcher, Catherine Walshe, will contact you and arrange a time to come to see you. This will probably be at your home, but you can choose to see her somewhere else if you prefer. She will answer any questions you may have about the study and ask you to sign a form agreeing to take part in the study.

There are two parts to the study. You may agree to take part in any or all of these parts. They may take place in any order. Firstly, the nurse researcher will make an appointment to talk to you about your experiences of community health care services. It is all right to have someone else there such as friends and family if you
wish. This interview will probably last for between 30 minutes and an hour. If you agree, the interview will be tape recorded to help the nurse researcher to remember what you said. Second, the nurse researcher will look at the notes the health care professional has made about their care of you with your permission.

**What are the possible disadvantages and risks of taking part?**
There should be no risks to you in taking part in this study. It is possible that some people may get upset when talking about some parts of their illness or care. If this happens to you, then the nurse researcher will ask if you want to stop the interview, or to continue at another time. You will be given information on other people to contact if there are issues or feelings you want to talk about more.

**What are the possible benefits of taking part?**
You may find it helpful to talk to someone about the care you have received. We hope that the information from this study will help us to provide better community health care services in the future.

**What if something goes wrong?**
It is unlikely that you will come to any harm by taking part in this study. However, if you are unhappy with any aspect of the way that you are treated, you should inform either your health care worker or the researcher. You may also make a complaint to the project advisory group. Any complaint that you might make will be taken very seriously. In order to protect you further, the project will be covered by the University of Manchester’s insurance for research studies.

**Will my taking part in this study be kept confidential?**
All information that is collected about you during the course of the research will be kept strictly confidential. Any information stored about you (such as notes from the interview) will have your name and address removed so that you cannot be recognised from it. All the notes and/or tape recordings that may have been made will be securely stored and destroyed after a period of time. Your general practitioner will, with your agreement, be told that you are involved in the study.

**What will happen to the results of the research study?**
When this study is finished we will publish the results in medical journals, so that other doctors and nurses can learn from the results. You will not in any way be identified in any report or publication. You can request that a report is sent to you at the end of the study.

**Who is organising and funding the research?**
This research is being completed as part of studies for a higher degree in nursing at the University of Manchester. The researcher is supported by an award from the Department of Health.

**Who has reviewed the study?**
The study has been reviewed by the (insert name) Local Research Ethics Committee. It was also reviewed by experts in research from the Department of Health who agreed the study was useful and should be funded.

**Contacts for further information.**
Thank you for taking the time to read and consider this information. Please feel free to discuss it with others (e.g. your family) before deciding whether or not to take part. If you have any further queries, please do not hesitate to ask. You can contact the nurse researcher directly as follows:

Catherine Walshe
The School of Nursing, Midwifery and Social Work
University of Manchester
Coupland III
Oxford Road
Manchester
M13 9LP

Tel: 0161 275 8700
e-mail: catherine.walshe@manchester.ac.uk

If you would like independent advice about the study before deciding whether or not to take part, you can speak with a member of the study’s advisory group, who can be contacted as follows.

Dr Bernadette Ryan Woolley
The School of Nursing, Midwifery and Social Work
Gateway House
Piccadilly South
Manchester

Tel: 0161 237 2159

We would be very grateful if you would complete the enclosed reply slip – whether you decide to take part in the study or not – and return it to us in the stamped addressed envelope enclosed. If you decide not to take part, your health care workers will not mind and your treatment will not be affected in any way. If you do decide that you want to take part, the nurse researcher will contact you to make and appointment to come and speak with you. If you decide to take part in the study you will be given a copy of this information sheet to keep. You will also be asked to sign a form indicating that you agree to take part, and will be given a copy of that form to keep as well. Thank you.
Appendix fourteen – Consent form for patients


Centre Number:
Study Number:
Patient Identification Number for this study:

CONSENT FORM

Title of Project: Community health care services: investigating referral decisions

Name of Researcher: Catherine Walshe

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2003 (version 3) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that sections of any of my healthcare notes may be looked at by Catherine Walshe from the University of Manchester. I give permission for her to have access to my Healthcare records.

4. I give permission for the researcher to contact my General Practitioner, to inform them that I have participated in this study.

5. I give permission for the interview which I give to be recorded. I understand that this recording will be securely stored, and destroyed after a period of time.

6. I agree to take part in the above study.

________________________ _____________________
Name of Patient Signature Date

_________________________ _____________________
Name of Person taking consent Signature Date (if different from researcher)

_________________________ ______________________
Researcher Signature Date

1 for patient; 1 for researcher; 1 to be kept with medical notes
Appendix fifteen – Data extraction form to use with patient notes

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### Referral information

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<th>--/--/--/----</th>
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Referral source:

Reason for referral:

Referral details:

Comment/Notes:

### Assessment information

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Joint assessment

Yes | No

Other assessors:

Diagnosis:

Prognosis:

Themes explored in assessment
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<th>Case study code:</th>
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### Appendix sixteen – Topic guides for interviews

#### Interview topic guide for Health Care Professionals

<table>
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<th>HCP ref:</th>
<th>Role:</th>
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<thead>
<tr>
<th>Interview topic areas</th>
<th>Field notes/observations</th>
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**Mapping palliative care in PCT**
- What services are there?
- What does each service do?
- Structures of palliative care
- Describe structure of own service
- Position of self/team within the organisation.
- PCT and palliative care.

**Public processes of palliative care**
- Policies and procedures, referral criteria about palliative care provision.
- Meetings to discuss referral and assessment?

**Sources of referral**
- Source of referral
- Reasons for referral

**Process of referral**
- **Sequencing** – when do referrals happen, are professionals referred to in a particular order?
- **Critical junctures** – what triggers a referral? Timing, appropriate?
- **Barriers and facilitators to referral** – what helps a referral, what hinders a referral.
- **Relationships with referrers** - Compare non referring professionals to referring professions.
- **Differences** – are any groups of patients treated/referred differently? Are any individuals or professions different in referring?
- **Response to referral** - Working patterns? Speed of response. Service constraints, prioritising, delegating Request permission of other professionals? Conflict and conflict resolution?

**Referring onwards** – how do you make decisions, who refers on. Involvement of self following referral onwards? Onwards referral affecting own role?

**Influences and relationships**
- What influences you to refer and assess in the way you do?
<table>
<thead>
<tr>
<th>Others perception of your role. Relationships with other professionals. View of the work of other professionals.</th>
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<tbody>
<tr>
<td><strong>Background/experience</strong></td>
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<tr>
<td>Length of time in role – other pall care work experiences.</td>
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<tr>
<td>Other issues</td>
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<tr>
<td>Identify other key informants</td>
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<td>Identifying patient to interview</td>
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<td>Identifying documents</td>
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<tr>
<td>Interview topic guide for Key Informants</td>
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<tr>
<td>Interview topic areas</td>
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**Mapping palliative care in PCT**

What do you understand by the term palliative care. List services provided within PCT

**Processes within PCT**

*Prioritising*

How does the PCT prioritise – how are decisions made and where does palliative care fit in with these priorities.

*Commissioning*

How do you commission palliative care – what influences your decisions and choices.

How do you decide what palliative care services are needed. Involvement of stakeholders.

Differences between commissioning and funding of NHS/voluntary providers of palliative care.

Arrangements with other PCT’s/bodies – joint working?

**Policies/strategies**

Strategic aims and objectives of palliative care within PCT

Identify current palliative care strategy and policy – what has influenced this, how developed. Aims and priorities of strategy/policy.

Congruence between strategy/policy and reality

**Managing palliative care services**

Palliative care structures and processes within PCT

Key groups/committee’s etc. Modes of working and
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<th>influence. Monitoring arrangements (workload/caseload/referrals)</th>
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<tr>
<td>Lines of communication and management</td>
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<tr>
<td>Discuss perceptions of palliative care providers, and of relationships between them</td>
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**Personal views/other issues**

Identify other key informants

Identify documents
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<tr>
<th>Interview topic guide for Patients</th>
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<tr>
<td>Interview topic areas</td>
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**Mapping home care for patient**

Identify all those currently caring for patient in the community

Patient view of role/function/key worker

If recently referred/assessed or ask to think back to referral/assessment to one or more services mentioned above

**Expectations of referral (who made referral)**

**Process of referral and assessment.**

**Decisions made.**

**Relationship between expectations and decisions/care offered.**

**Involvement in process of referral, assessment and decision making.**

**Relationships between health care professionals**

**Other issues**

Opportunity for general comments on care received, identification of gaps etc.
## Appendix seventeen – Documentary evidence collected from the case study sites

### Case study A

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### Appendix eighteen – Thematic framework used for coding data

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| **Working with other professionals** | Discharge  
Information gathering  
Sequence of care  
Transfer from active to palliative  
Tool to access other services  
Referral criteria  
Referral allocation  
Active case or referral management  
Anticipatory referrals or planning  
Evaluating the work of others  
Being a threat to others  
Inter-professional relationships  
Judging other professionals  
Teamwork  
Communicating with others  
Key worker role  
Negotiating roles  
Working as a team  
Working as an individual  
Aware this persons around  
Working with hospital staff  
Team leadership  
Hub and spoke model  
Specialist vs. Generalist roles  
Advisory or invitational role  
Referring to others  
Awareness of other working patterns  
Knowing the team  
Conflict with non palliative care work  
Knowing about other services  
Understanding what district nurses do  
Understanding what Macmillan nurses do  
Everybody works differently  
Complexity of palliative care  
Role changes over time  
Affecting care quality  
Shying away from palliative care  
Status of palliative care  
Having a special interest  
Improving care quality  
Covering all the angles  
Fallen through the net  
**Working with patients**  
Knowing the patient  
Professionals interpretation of patient needs  
Support through active treatment |
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Appendix Nineteen – Extract from a coded interview

I: Right. So how would you describe the role of the Macmillan nurse in the community then?

Well, I think from my perspective they're like an expert kind of stop-in service if, if I went to access the patient, and I was, I was dealing with some sort of psychological issues or coping mechanisms related to their illness, if it was something beyond my experience and expertise then I would refer on. Because they, although they, although they don't visit every patient, because of that knowledge, and background, and because they know all these different types of chemotherapy and they have all the connections and things, I think they have the ability to have a better understanding about palliative care, that's all. So, and they're specifically doing that, so, whereas a District Nurse.

I'm a Jack of Many Trades, they're doing palliative care only in that respect, so they, they will know. So if I've got a chemo medication query sometimes, rather than ringing the GP, I would ring the Macmillan Nurse and say, you know, 'What, what should I do about this, the patient's still got a pain, but they're on that or they're this, and what should I do? Should I put another something in the driver, because they've got a side effect, so I would ask their advice first, and then I would go to my GP, and say, 'this patient is suffering with that,' and then I spoke to a Macmillan nurse, and it's kind of like, it's another kind of authority, because I've asked somebody else's opinion is of greater experience then you know, it's substantive.

I: Right.

So then the GP is more inclined to say, 'well that sounds like a good idea, and we'll go with that'. So, I do, I do see them as a support service, but I also think they do a lot of teaching and development with the District Nurse Service. We had a, we ran a pilot in '97 where the Macmillan Nurse, because we were having problems accessing training, just because of the different shift patterns and things, and we have a lot of part-time staff, and they aren't getting into training, and they're feeling a little bit disillusioned, and it's quite, I think it's quite intense when you're visiting a palliative care patient, it's just you and then, and they're pouring out their heart and worries, and family dynamics and the rest of it, so the nurse needs that training and development, and the Macmillan nurses do that, and the Macmillan nurse is coming to us, to our base, and teaching us about how to manage anxiety, how to manage fatigue, looking at like breathlessness and, and pancy, kind of symptom issues, and you know, all the other things because, if you go on course, if it's generally the pain, nausea, vomiting, constipation, it's the general stuff covered, and we were looking at complicated cases really, and what our experience was. So, they've got quite a diverse role really.

I: Yeah, yeah, so how does the process actually work? Is there one Macmillan Nurse that works with a group of District Nurses and surgeons, or does it not work like that at all?

Um, I'm not too sure, because we're recently undergone some reorganisation with their team, but all I know is that if I ring in, I can speak to any of them really. They're not, they're not specific, um, I think that if they're visiting a patient they're specific, unless they're on holiday and they cover each other, but I'm not sure if it's GPs attached or District Nurse teams attached, or area, because some areas have high or low deprivation, I think, the Macmillan nurse would really have a lot to do in those areas, so,

I: Right. So how many Macmillan Nurses are there?

Um, at the last count, before sickness, (laughs) at the last count before sickness I think there's six. But somebody's gone on to do a recruitment, and somebody else is on maternity leave, and somebody else is off poorly, so,

I: And that six are just for the community, or is that the hospital?
I think, I think that it also includes the hospital. As well, so, it’s not, I mean when you think about it it’s not a lot really for the work and numbers that they cover, but then again from my perspective, they don’t see all of my palliative care patients, so it’s not like they’re seeing everybody. They’re seeing relatively the palliative care patients that have the greatest specialist need, as I see it, so they can be a little bit selective, and a lot of their consultations they can do as well on the telephone. So they ring and make contact with patients and say, “how’s your pain been”, and things like that rather than visiting all and sundry. Because they just wouldn’t manage to do it realistically, so, it’s just utilising their resources better.

I: Yeah, so roughly what proportion of your patients, palliative care patients that you see as a District Nurse then would you refer to the Community Macmillan Team?

Um about 5 or 10% No, not quite a, yeah quite a small proportion, but then again I think for our team we have a lot of palliative care experience, so and I think, I think it has a lot to do with it, because I have worked with other district, before I became a Sister I worked with other Sister’s who referred everybody point-blank, as soon as they were diagnosed with cancer, referred to Macmillan, and got the ball rolling, and intervention started straight away. And I’ve seen the “why”, and you know “against” of that, but, but, I thought, because we’ve got nurses in there who’ve done the Care of the Dying course, um, we’ve got a high proportion of palliative care patients and that is a lot to do with our G.P.’s who are, I’m, I’m very lucky with the G.P.’s that I’m attached to, and they do Hospice Clinic sessions. So they, we, they pick up and manage at home for a long period of time these palliative care patients, whereas other G.P.’s and this isn’t being critical, who have felt, who haven’t had that expertise, have, have often admitted them somewhere because they feel it’s out of their control, so we tend to keep, as a professional group, we tend to keep our patients at home for longer, so we’ve had exposure to that, I mean I mean to have used use the same guide, well we have a check list that we check the dates and batch numbers and things like that on when it’s been reviewed, and we, our team have used it more than anybody else. So it’s, either, it’s just coincidental, or it is that we’ve been exposed. So that exposure means that actually we’ve got quite a lot of experience so it’s only when I think that people feel that it’s getting beyond them, and beyond me, although everyday every day is a new experience that we make, right, actually now I think we need is that somebody else’s a different style and style. So, you know, and then I’m not sure whether that’s the right way to do it, I mean it, in some ways like I like to be self-sufficient, and manage the patients in a team, and they get used to you, and the relationship builds and then you know all their thoughts and feelings and emotional, psychological aspects come out, but sometimes sometimes if you’re at the point of referral, if you create everybody it becomes a bit bombastic, and like “oh, who are you, and what are you for”, and it’s hard on the relationship, but then by talking to a Macmillan Nurse in later, their relapse, I sometimes like to have it in the relationship to build between the Macmillan Nurse and the patient, do you see what I’m saying, And that must be hard for them, but then I’m, I’m thinking I’m trying to alleviate their workload in the, this instance.

I: So if you’re thinking that about the, you know, the patient that you might be referring on, um, obviously you’re judging when you’re reaching the limits of your expertise, so what sort of thing?

would, would trigger that sort of referral? What are the sorts of issues that you think, “right, I need to involve somebody else here?”

Well we do an assessment for our patients, and for palliative care patients I’m the type of District Nurse that likes monitoring patients quite closely. Now some District Nurses, with, you know the cancer support nurses which are very generalist, but they look at the, how the patient is managing day-to-day, daily activities, how the relationships are between family members, next of kin, carers, if you have a Care Package, how that is going, how on earth’s that, and all the, the whole shebang, so we visit our patients quite regularly. Now other District Nurses that you may meet may not do that.
Appendix twenty – Example of part of a chart

Example of part of chart for case study ‘B’ examining some issues of teamwork for interviewees.

<table>
<thead>
<tr>
<th>Communicate with others</th>
<th>Key worker role</th>
<th>Negotiating roles</th>
<th>Working as a team</th>
<th>Advisory role</th>
<th>Generalist or Specialist</th>
</tr>
</thead>
<tbody>
<tr>
<td>B/SD1</td>
<td>DNs should be involved in everybody via protocol, but reality is that very stretched, so unable to do so. Key worker variable. – who is most involved and who patient turns to.</td>
<td>Some GPs concerned about hospice take over, negotiate shared care. HAH not always used well, but good after last review. MN and GP can use PM in care negotiations.</td>
<td>Based at hospice, even if employed by different orgs, so try to work as a team. Specs try to work alongside generalists – imparting skills and wisdom. Greatest benefit to patients is from whole team. More strategic now, less overlap. Hospice meet daily, discuss referrals, iron out conflicting info.</td>
<td>Need to be a source of help and advice as well as hands on role. How much do we send the troops in and how much do we have a watchful presence. Attractive service. Try not to argue. Best care for patients is a palliative partnership – home with skilled, experienced and appropriate care. Shouldn’t be at home struggling.</td>
<td>Specialist palliative care works alongside, support, advice, wisdom. Bail out generalists or have a watchful presence. Hospice is an attractive service because of the package of care. Can inadvertently undermine primary care teams. Hospice expectations can be unrealistic.</td>
</tr>
<tr>
<td>B/GP1</td>
<td>DNs more proactive, GP reactive. Good relationship so always work things out. DNs got better communications systems with hospital. Planning comm. Strategies with GSF. Coordination happens by chance not design.</td>
<td>CMN is the coordinator of palliative care. They are like the GPs for palliative care. DNs are the lead health professionals for someone with pc needs. Access point to other services. Different people coordinate for different services. Need to identify a lead person rather than let it evolve.</td>
<td>DN proactive, GP reactive. Always just talk and work out problems. Mainly leave up to DNs, but depends on needs of the patient. If have formal processes, if people cant see gains quickly, they become disenchanted.</td>
<td>Refer to DNs as left.</td>
<td>Macmillan Nurses good advisors.</td>
</tr>
<tr>
<td>B/GP3</td>
<td>Geographical working and different teams makes communicating difficult. Try to communicate with OOH.</td>
<td>I have an overview, but sometimes DNs take on that role, but its not formally stated. If DN has interest and competence then appropriate to take on that role.</td>
<td>Roles can overlap. Sometimes few professionals involved, sometimes many. Tend to use Macmillan Nurses where don’t have regular DN input.</td>
<td>Team bigger, so more difficult to communicate with DN. Communication between DN and GP is central to care. Services should be offered by well trained generalists, not specialist palliative care.</td>
<td>Specialist support only when needed, not all care.</td>
</tr>
<tr>
<td>B/GP4</td>
<td>Systems of communicating who pc patients are. Communication from hospital very difficult. Fax referrals to DNs.</td>
<td>People forget GPs still key workers. Key because of background knowledge. It’s a core functions of a GP.</td>
<td>Don’t tend to get involved with hospice once they are in. You work it out by negotiation.</td>
<td>Referrals vary depending on services available and the staffing situation. Negotiate – it’s the hospices privilege to live with them, we’ve got to</td>
<td>Macmillan Nurses role is to provide advice. Most of the time would take their advice – have spent a long time with the patient. Ideal would be a service</td>
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<tr>
<td>B/SN1</td>
<td>Collaborative approach with DNS, either visit or bounce ideas. We always feed back to DNS. Always check out with DN first as potential for conflict. Need to know who is doing what. Make judgements depending on what the DN thinks issues are.</td>
<td>Model is the hospice being the hub of palliative care services. DNS are key workers along with the GP. GP has ongoing relationship. Specialist service is complementary. How do key workers meet needs.</td>
<td>As a specialist shouldn’t plug gaps, should feed awareness of need back to DNS. If GP refers, always ask if DN involved, and discuss with them first. Always feed back to DNS. Get DNS to go in and see if specialist input is needed. DNS can also refer for reassurance.</td>
<td>It’s a team orientated approach. Work closely with others, collaborative approach, work alongside DNS. Use DN judgements on referrals.</td>
<td>Potential for DN overlap with Macmillan Nurses because of variable skills. Specialist workers are complementary to the core DN and GP team. Some generalists like specialist palliative care in, even if they are very experienced.</td>
</tr>
<tr>
<td>B/SN2</td>
<td>We do all try to communicate, but not easy. People get us mixed up. Liaison is very good. Everybody working together for the good of a young lady. Have daily hospice meetings. HAH have had to work very hard on communication.</td>
<td>Emphasise that DN and GP are first port of call. DN is key worker.</td>
<td>As a MN need to know your GPS and how to negotiate with each one of them. – once blown it, blown it. Some blanket referrals to MN that should go to DN. HAH complement the DN service. Some duplication with ‘B’ care pathway service.</td>
<td>All hoping to sing from same hymnbook. Advice needs to be consistent. Frustrating when someone changes treatment who doesn’t know pt. Feel that (young person) is getting the best care because of the teamwork. Liaise with HAH to share care. ‘B’ care pathways good – liaison.</td>
<td>Patients perceptions of DN and MN very different. Think Macmillan Nurses have more time. Use MN for support, not visits. Others listen more if got advice from specialist palliative care. Macmillan Nurses are like an add on – support. Patients can see Macmillan nurse as superior service because of additional time.</td>
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<tr>
<td>B/SN3</td>
<td>Always refer to DNS. – we have feedback forms. Some duplication and difficulties communicating.</td>
<td>DN should be the key person.</td>
<td>Difficult to carve role when known to be temporary.</td>
<td>‘B’ care pathway difficulties because not attached to palliative care teams/hospice.</td>
<td>Specialist palliative care services attached to ‘B’ pathway service are more geared up. Some specialists think they are the only ones who can manage a problem.</td>
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<tr>
<td>B/AH1</td>
<td>Need to work closely with nurses. Don’t make referrals, just liaise. People get different perceptions of what is happening.</td>
<td>Role is care management. Key role in coordinating discharges. Coordination of ongoing community care poor. Don’t link well with the Macmillan nurses. Don’t like to lose control when patients go home. DNS are well placed to coordinate.</td>
<td>Can have disagreements about services in case conferences. Have to sometimes negotiate what you think to be the ‘right’ care.</td>
<td>Liaise closely with nurses when setting up care packages. – daily updating conversations. Example of DNS changing care package. Tension between health and social care. Feel that Macs are separate from hospice, don’t know why not linked up with them.</td>
<td>Specialist social workers for pc more appropriate. Can develop relationships. Needs case work and follow through.</td>
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<tr>
<td>B/AH2</td>
<td>Have done a key worker pilot – but in practice</td>
<td>Can do joint visits. Still have to refer via GP or MN.</td>
<td>Acts as a resource. Developed own specialism.</td>
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<td>Communicate with others</td>
<td>Key worker role</td>
<td>Negotiating roles</td>
<td>Working as a team</td>
<td>Advisory role</td>
<td>Generalist or Specialist</td>
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<tr>
<td>B/AH3</td>
<td>Always discuss with others.</td>
<td>GPs in background because of expertise of dieticians.</td>
<td>Team involved depends on their needs.</td>
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<tr>
<td>B/DN1</td>
<td>Protocol to communicate with DNs via the hosp nurses. Meet with GPs on different basis – weekly, fortnightly, monthly. Ring and e-mail communications. Have communication proforma for ooh. Sometimes is professional conflict between services.</td>
<td>GPs do swap pc patients. We should be the first port of call, and have expertise to see who needs referring. DN is care coordinator, sits in middle, services feed back to us. Doesn’t always work.</td>
<td>Do inform GP out of respect – but leave me to it.</td>
<td>Suspicious of GP when he did visit daily. Inform GP out of respect, but don’t really want to know. HAH are ‘supplementary service’ to DNs, RR provide more time. Go to understand other services and have professional respect. But lots of power control issues between teams.</td>
<td>DN jack of all trades, Macmillan nurses only pc so have better knowledge. Substantive knowledge. Tap into MN expertise. Macmillan nurses more selective. Only refer when got beyond me.</td>
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<tr>
<td>B/DN2</td>
<td>Can be ‘who is in charge’ issues between Consultant in Palliative Medicine and GP. No regular meetings to talk about pc. Communication not always satisfactory.</td>
<td>DNIs have key role because follow patient through, even if not visiting [i.e. concept of follow through even if not actively involved] We are the named nurse. Different services not coordinated very well. Everything got to be linked in together.</td>
<td>Have shared care with Macmillan nurses – works well. Macmillan nurses will refer patients to DNIs (workload), refer on if can’t handle.</td>
<td>Can be leadership issues. Some teams use HAH for shared care, I refer to look after own..</td>
<td>Advice can lead to problems with who is in charge. Do provide a lot of advice and teaching. Some people may prefer to be referred to Macmillan nurses.</td>
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<td>B/DN3</td>
<td>Macmillan nurses always let DNIs know if had patient referred. Too many people provide telephone numbers for patients. Confusing. Liaising and communicating is part of role. Down to communication and relationships that facilitates care. GSF had benefits, but already had regular access to GPs.</td>
<td>Confusing – too many telephone numbers in the house. DN is key worker.</td>
<td>Organisation needs to be discussed before any new service is set up.</td>
<td>Do joint visit with MN if patient not keen. Has to be right sequence of events i.e. talk to GP first. GP for MN would ask CPM, not ask directly. HAH there as a support for DN in providing care.</td>
<td>Specialists are a resource. Specialist palliative care is a resource. All of them known to specialist palliative care at some point. GPs more reluctant to access specialist palliative care than nurses.</td>
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<tr>
<td>B/DN4</td>
<td>Visit with MN so know what saying to patients. DNIs always primary carers. Do communicate well.</td>
<td>DNIs always remain primary carers. GPs don’t have a big role. DN always coordinator if involved – trust policy.</td>
<td>Pts come to DNIs first, as Macmillan nurses will pass them on. Work well with homecare on shared and tapered care.</td>
<td>Consultant in Palliative Care there as a back up. Still visit if patient going to day hospice. GPs don’t have a big role in pc. Refer to home care in</td>
<td>Don’t always need to visit, can ring for advice. Could do with 24/7 number. SPC useful as generalists don’t always have time or knowledge. Inform Macmillan nurse of all patients, but only send complex patients to them. Complex</td>
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<td>Communicate with others</td>
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<td>Negotiating roles</td>
<td>Working as a team</td>
<td>Advisory role</td>
<td>Generalist or Specialist</td>
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<td>early stages, share care later, then they pull out.</td>
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<td>patients – we can’t solve problems but Macmillan nurses can. Use profs to bypass others.</td>
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<tr>
<td>B/P1</td>
<td>Have a sense that all professionals involved communicate. Hospice and DNs both have roles in coordinating care.</td>
<td>DN is key person for me. Hospice also good at coordination</td>
<td>DN hands on, MN pain relief. Now DN fine, but know she will access expertise if required.</td>
<td>Knows that DNs will turn to others for advice if needed.</td>
<td>Got MN and DN – OK with DN.</td>
</tr>
<tr>
<td>B/P2</td>
<td>Lack of communication from hospital caused problems.</td>
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<tr>
<td>B/P4</td>
<td>Consultant lead in pain control, coordinates care.</td>
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<tr>
<td>B/P5</td>
<td>PN has maintained contact. Quite impressed at interaction between healthcare professionals, but not aware of interaction between DN and MN.</td>
<td>Don’t get a sense of there being one person who coordinates care. Do get impression of communication, but not coordination.</td>
<td>DN linked me up with others.</td>
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<td>DN more involved than MN.</td>
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This population based needs assessment for palliative care follows the format suggested by Tebbit (2004).

**Step 1: Defining the populations to be assessed**

It can be seen from Table 1 that the primary care trusts studied serve populations of very different sizes, with the population of case study site B being more than double that of case study site A.

<table>
<thead>
<tr>
<th>PCT resident population (2001 census)</th>
<th>Population a</th>
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<tbody>
<tr>
<td>Case study A</td>
<td>118 208</td>
</tr>
<tr>
<td>Case study B</td>
<td>261 037</td>
</tr>
<tr>
<td>Case study C</td>
<td>139 125</td>
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</tbody>
</table>

Table 1 The resident population for case study sites A, B and C

\(^{a}\) Data supplied from the National Database for Primary Care Groups and Trusts based on 2001 census data. The National Database for Primary Care Groups and Trusts is a product of the National Primary Care Research and Development Centre at the University of Manchester. It was devised by Dr Deborah Baker, who is the database director. The database was constructed by Justin Hayes at the Regional Research Laboratory, School of Geography, University of Manchester (Director: Dr Robert Barr); SEE IT consultancy designed and built the map interface. We are grateful to Andrew Wagner, Mark Hann and David Reeves (NPCRDC) for their considerable hard work in cleaning and validating the data sets. Andrew Wagner is the database manager (a.wagner@man.ac.uk).

**Step 2: The Epidemiological approach – annual incidence of deaths**

Table 2 shows that the death rates within the primary care trust areas differ, with case study A having a rate of cancer death which is much higher than either of the other two sites, and which is also considerably greater than the England and Wales average. The other two sites have cancer death rates lower than average, particularly case study site C.
Table 2  Death statistics for case study sites A, B and C

<table>
<thead>
<tr>
<th>Case study site</th>
<th>Population</th>
<th>All deaths</th>
<th>Cancer deaths</th>
<th>Cancer deaths as % of all deaths</th>
<th>All deaths per 100 000 population</th>
<th>Cancer deaths per 100 000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (^b)</td>
<td>118 208</td>
<td>1 181</td>
<td>326</td>
<td>28%</td>
<td>997</td>
<td>275</td>
</tr>
<tr>
<td>B (^c)</td>
<td>261 037</td>
<td>2 731</td>
<td>655</td>
<td>24%</td>
<td>1046</td>
<td>251</td>
</tr>
<tr>
<td>C (^d)</td>
<td>139 125</td>
<td>1364</td>
<td>319</td>
<td>23%</td>
<td>978</td>
<td>229</td>
</tr>
<tr>
<td>England and Wales (^a)</td>
<td>537 877</td>
<td>133 490</td>
<td>25%</td>
<td>1034</td>
<td>256</td>
<td></td>
</tr>
</tbody>
</table>

\(^a\) ONS 2001 census data.  
\(^b\) Data provided by PCT information analyst and is an average of 2002 – 2004 figures.  
\(^c\) Data provided from PCT public health annual report – 2002 figures.  
\(^d\) Data provided from PCT information analyst – 2001 figures.

Step 3: The epidemiological approach – prevalence of problems/symptoms

Tables 3 and 4 provide estimations of the prevalence of problems and symptoms in people with cancer and progressive non-malignant disease within each case study site in the last year of life.

Table 3  Estimations of the prevalence of problems and symptoms in people with cancer within each site in the last year of life

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>% with symptom (^a)</th>
<th>Case study A</th>
<th>Case study B</th>
<th>Case study C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer deaths within PCT</td>
<td></td>
<td>326</td>
<td>655</td>
<td>319</td>
</tr>
<tr>
<td>Pain</td>
<td>84%</td>
<td>274</td>
<td>550</td>
<td>268</td>
</tr>
<tr>
<td>Trouble with breathing</td>
<td>47%</td>
<td>153</td>
<td>308</td>
<td>150</td>
</tr>
<tr>
<td>Vomiting or feeling sick</td>
<td>51%</td>
<td>166</td>
<td>334</td>
<td>163</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>51%</td>
<td>166</td>
<td>334</td>
<td>163</td>
</tr>
<tr>
<td>Mental Confusion</td>
<td>33%</td>
<td>107</td>
<td>216</td>
<td>105</td>
</tr>
<tr>
<td>Depression</td>
<td>38%</td>
<td>124</td>
<td>249</td>
<td>121</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>71%</td>
<td>231</td>
<td>465</td>
<td>226</td>
</tr>
<tr>
<td>Constipation</td>
<td>47%</td>
<td>153</td>
<td>308</td>
<td>150</td>
</tr>
<tr>
<td>Bedsores</td>
<td>28%</td>
<td>91</td>
<td>183</td>
<td>89</td>
</tr>
<tr>
<td>Loss of bladder control</td>
<td>37%</td>
<td>120</td>
<td>242</td>
<td>118</td>
</tr>
<tr>
<td>Loss of bowel control</td>
<td>25%</td>
<td>81</td>
<td>164</td>
<td>80</td>
</tr>
<tr>
<td>Unpleasant smell</td>
<td>19%</td>
<td>62</td>
<td>124</td>
<td>61</td>
</tr>
</tbody>
</table>

\(^a\) Percentage figures from Tebbit (2004)
### Table 4
Estimations of the prevalence of problems and symptoms in people with progressive non-malignant disease within each site in the last year of life

<table>
<thead>
<tr>
<th>% with symptom</th>
<th>Case study site A</th>
<th>Case study site B</th>
<th>Case study site C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-cancer deaths with palliative care need</td>
<td></td>
<td>570</td>
<td>1352</td>
</tr>
</tbody>
</table>

**SYMPTOM**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Case study site A</th>
<th>Case study site B</th>
<th>Case study site C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>67%</td>
<td>382</td>
<td>906</td>
</tr>
<tr>
<td>Trouble with breathing</td>
<td>49%</td>
<td>279</td>
<td>662</td>
</tr>
<tr>
<td>Vomiting or feeling sick</td>
<td>27%</td>
<td>154</td>
<td>365</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>36%</td>
<td>205</td>
<td>487</td>
</tr>
<tr>
<td>Mental Confusion</td>
<td>38%</td>
<td>217</td>
<td>514</td>
</tr>
<tr>
<td>Depression</td>
<td>36%</td>
<td>205</td>
<td>487</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>38%</td>
<td>217</td>
<td>514</td>
</tr>
<tr>
<td>Constipation</td>
<td>32%</td>
<td>182</td>
<td>433</td>
</tr>
<tr>
<td>Bedsores</td>
<td>14%</td>
<td>80</td>
<td>190</td>
</tr>
<tr>
<td>Loss of bladder control</td>
<td>33%</td>
<td>188</td>
<td>446</td>
</tr>
<tr>
<td>Loss of bowel control</td>
<td>22%</td>
<td>125</td>
<td>297</td>
</tr>
<tr>
<td>Unpleasant smell</td>
<td>13%</td>
<td>74</td>
<td>176</td>
</tr>
</tbody>
</table>

*a* Percentage figures from Tebbit (2004)

### Step 4: Epidemiological approach – place of death and place of care.

Table 5 displays the percentages of those with cancer dying at home within each case study site. This shows that the percentages of those dying at home are similar, despite some very different patterns of care provision. All have home death figures below the national average. Where the differences appear is in the percentages of those dying outside the home. The most notable differences appear to be in the percentages of those dying in hospice – where there is a difference of 9% between those in case study A and those in case study C.

### Table 5
Percentages of those with cancer dying at home within each case study site

<table>
<thead>
<tr>
<th>Case site study</th>
<th>Home</th>
<th>Hospital</th>
<th>Hospice/SPC unit</th>
<th>Care home</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>23%</td>
<td>48%</td>
<td>23%</td>
<td>4%</td>
</tr>
<tr>
<td>B</td>
<td>22%</td>
<td>49%</td>
<td>20%</td>
<td>8%</td>
</tr>
<tr>
<td>C</td>
<td>20%</td>
<td>53%</td>
<td>14%</td>
<td>11%</td>
</tr>
<tr>
<td>National figures</td>
<td>25%</td>
<td>47%</td>
<td>17%</td>
<td>12%</td>
</tr>
</tbody>
</table>

*a.* cancer deaths 2002 – 2004 provided by PCT information analyst

*b.* cancer deaths 2002 – 2003 provided by PCT information analyst

*c.* cancer deaths 2002 provided by PCT information analyst

*d.* Figures from Tebbit (2004).
Step 5. Demographic approach – Age structure of the population

Tebbit (2004) argues that the key age structure factor affecting palliative care need is likely to be the numbers of people aged 60 and over. It can be seen from Table 6 that each area has a percentage of over 60’s lower than the national average, although it is particularly low in case study C. This is the likely explanation of the low death rate within this case study site. However, the site with the highest death rate (A) also has a low proportion of those aged over 60, so other factors are obviously coming into play in this case which are affecting cancer deaths in particular.

Table 6 Percentages of those who are aged over 60 within each case study site

<table>
<thead>
<tr>
<th>Case study site</th>
<th>% aged over 60</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>18%</td>
</tr>
<tr>
<td>B</td>
<td>20%</td>
</tr>
<tr>
<td>C</td>
<td>14%</td>
</tr>
<tr>
<td>England</td>
<td>21%</td>
</tr>
</tbody>
</table>

(Data source – Office of National Statistics 2001 census data)

Step 6: Demographic approach – number of males and females

Table 7 displays the proportions of males and females within each case study site who are over 60 and over 75. This data demonstrates the percentage of females who may outlive their partner and therefore live alone requiring additional care. The percentages of elderly males and females within these age groupings in the case study sites are remarkably similar – indicating similar levels of potential need.

Table 7 Percentages of males and females over 60 and over 75 within each case study site

<table>
<thead>
<tr>
<th>Percentage of males over 60</th>
<th>Percentage of females over 60</th>
<th>Percentage of males over 75</th>
<th>Percentage of females over 75</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>44%</td>
<td>56%</td>
<td>37%</td>
</tr>
<tr>
<td>B</td>
<td>44%</td>
<td>56%</td>
<td>38%</td>
</tr>
<tr>
<td>C</td>
<td>45%</td>
<td>55%</td>
<td>37%</td>
</tr>
</tbody>
</table>

(Data Source – ONS census data 2001)

Step 7: Demographic approach – ethnic composition and religion of the population

Tables 8 and 9 display the ethnic and religious compositions of the case study site populations. Case study A is the most mono-cultural, with a predominantly white, Christian population. Case study B has an Asian and Muslim population greater than the England average. Case study C is the most mixed ethnically, with fewer white people than the national average, and larger populations of mixed, Asian, black and Chinese origin than the national average.
Table 8  Percentages of those from different ethnic backgrounds within the primary care trust areas

<table>
<thead>
<tr>
<th>Case study site</th>
<th>White</th>
<th>Mixed</th>
<th>Asian or Asian British</th>
<th>Black or black British</th>
<th>Chinese or other ethnic group</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>99%</td>
<td>&lt;1%</td>
<td>&lt;0.5%</td>
<td>0.6%</td>
<td>&lt;0.5%</td>
</tr>
<tr>
<td>B</td>
<td>89%</td>
<td>1%</td>
<td>9%</td>
<td>0.6%</td>
<td>&lt;0.5%</td>
</tr>
<tr>
<td>C</td>
<td>69%</td>
<td>4%</td>
<td>15%</td>
<td>9%</td>
<td>3%</td>
</tr>
<tr>
<td>England</td>
<td>91%</td>
<td>1%</td>
<td>5%</td>
<td>2%</td>
<td>1%</td>
</tr>
</tbody>
</table>

(Data source – Office of National Statistics 2001 census data)

Table 9  Percentages of those from different religious backgrounds within the primary care trust areas

<table>
<thead>
<tr>
<th>Case study site</th>
<th>Christian</th>
<th>Buddhist</th>
<th>Hindu</th>
<th>Jewish</th>
<th>Muslim</th>
<th>Sikh</th>
<th>Other</th>
<th>None</th>
<th>Not stated</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>84%</td>
<td>&lt;0.1%</td>
<td>0.1%</td>
<td>&lt;0.1%</td>
<td>0.1%</td>
<td>&lt;0.1%</td>
<td>0.1%</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>B</td>
<td>75%</td>
<td>&lt;0.1%</td>
<td>2%</td>
<td>&lt;0.1%</td>
<td>7%</td>
<td>&lt;0.1%</td>
<td>0.1%</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>C</td>
<td>52%</td>
<td>0.7%</td>
<td>1%</td>
<td>0.5%</td>
<td>15%</td>
<td>0.7%</td>
<td>0.4%</td>
<td>18%</td>
<td>10%</td>
</tr>
<tr>
<td>England</td>
<td>72%</td>
<td>0.3%</td>
<td>1%</td>
<td>1%</td>
<td>3%</td>
<td>0.6%</td>
<td>0.3%</td>
<td>15%</td>
<td>8%</td>
</tr>
</tbody>
</table>

(Data source – Office of National Statistics 2001 census data)

Step 8:  Demographic approach – living in households

Table 10 displays information about those who are living alone within the case study site. If an individual is living alone it can be argued that informal support in the palliative phase of an illness may be harder to provide, and this may affect either the rates of those dying at home, or the amount of professional support required. Whilst the numbers of those in single person households is large in case study C, it appears that this is predominantly younger single person households. A closer look at those who are older living alone demonstrates a percentage close to the national average, as are most of the study areas.

Table 10  Single person and pensioner households within the case study sites

<table>
<thead>
<tr>
<th>Case study site</th>
<th>Single person households</th>
<th>Pensioners living alone</th>
<th>Other all pensioner households</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>27%</td>
<td>13%</td>
<td>8%</td>
</tr>
<tr>
<td>B</td>
<td>31%</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>40%</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>30%</td>
<td>14%</td>
<td>9%</td>
</tr>
</tbody>
</table>

(Data source – Office of National Statistics 2001 census data)
Step 9:  The Socio-economic approach – indices of deprivation

It is argued that those living in more deprived areas require greater health care resources than those in more affluent areas. Tebbit (2004) argues that this is the second most important factor after annual incidence of deaths in determining palliative care need within an area. It can be seen from table 11 that all of the case study sites have areas of real deprivation, with few affluent areas represented within their boundaries. Case study C in particular has all of its wards in the top ranked 30% of deprived wards in England.

Table 11 Ward ranking of Indices of Multiple Deprivation for each case study site

<table>
<thead>
<tr>
<th>Case study site</th>
<th>No. of wards</th>
<th>Wards in top 10%</th>
<th>Wards in top 20%</th>
<th>Wards in top 30%</th>
<th>Wards in bottom 30%</th>
<th>Wards in bottom 20%</th>
<th>Wards in bottom 10%</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>21</td>
<td>10</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>B</td>
<td>20</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>C</td>
<td>11</td>
<td>9</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

(Data source – DETR Index of Multiple Deprivation 2000)

Step 10: The benchmarking approach

Table 12 Average of ward ranking for indices of multiple deprivation for each case study area.

<table>
<thead>
<tr>
<th>Case study site</th>
<th>Average of ward ranks</th>
<th>Rank out of 354 local authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>1593</td>
<td>18</td>
</tr>
<tr>
<td>B</td>
<td>2282</td>
<td>78</td>
</tr>
<tr>
<td>C</td>
<td>617</td>
<td>7</td>
</tr>
</tbody>
</table>

(Data source – DETR Index of Multiple Deprivation 2004)

Step 11: Benchmarking approach

The final step in the population based needs assessment for palliative care is to compare need – in this case between the three sites studied. The protocol suggested for this is to take the cancer deaths per 100,000, and ascribe an index value for that relative to the highest rate for any primary care trust. This is modified by a deprivation modifier which is calculated from the average of ward ranks for all local authority populations. The case study site with the least need is ascribed an index value of 100 and the relative index value of the other primary care trusts calculated from this. (Tebbit 2004). Table 13 shows these calculations for the three Primary Care Trusts studied – indicating that case study C has the lowest need and case study A the highest.
Table 13  Index of comparative need for the three case study sites.

<table>
<thead>
<tr>
<th>Case study site</th>
<th>Cancer deaths per 100 000</th>
<th>Index value</th>
<th>Deprivation modifier</th>
<th>Modified index value</th>
<th>PCT need index value</th>
<th>Effect on resource needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>275</td>
<td>94.3</td>
<td>1.94</td>
<td>182.9</td>
<td>117</td>
<td>+ 17</td>
</tr>
<tr>
<td>B</td>
<td>251</td>
<td>96.3</td>
<td>1.86</td>
<td>179.1</td>
<td>115</td>
<td>+15</td>
</tr>
<tr>
<td>C</td>
<td>229</td>
<td>78.8</td>
<td>1.99</td>
<td>156.8</td>
<td>100</td>
<td>-</td>
</tr>
</tbody>
</table>

(Data source: index value data from National Centre for Health Outcomes Development www.nchod.nhs.uk relative to the highest rate for any local authority in the country. C = city wide data. Effect on resource needed is relative to the lowest modified index value (C)).

The next step is to describe the service provision for palliative care within the primary care trusts to see if provision matches the difference in needs identified using these approaches.

Specialist palliative community care

Table 14  Comparison of suggested and actual provision of specialist palliative care provision within the case study sites.

<table>
<thead>
<tr>
<th>Case study A</th>
<th>Case study B</th>
<th>Case study C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suggested</td>
<td>Actual*</td>
<td>Suggested</td>
</tr>
<tr>
<td>Consultants (2.0 per million)</td>
<td>0.23</td>
<td>0.5</td>
</tr>
<tr>
<td>Nurses (23 per million)</td>
<td>2.7</td>
<td>3</td>
</tr>
<tr>
<td>Social Workers (0.8 per million)</td>
<td>0.09</td>
<td>0</td>
</tr>
<tr>
<td>Physio/OT (0.8 per million)</td>
<td>0.09</td>
<td>0</td>
</tr>
<tr>
<td>Pharmacist/dietician (0.8 per million)</td>
<td>0.09</td>
<td>0</td>
</tr>
<tr>
<td>Chaplain (0.6 per million)</td>
<td>0.09</td>
<td>? (available)</td>
</tr>
</tbody>
</table>

* WTE figures given where possible, but figures starred are numbers in post where WTE not known.