

**Equity, need and access in health care:
a mixed methods investigation of specialist palliative
care use in relation to age**

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of the requirements for the degree of
Doctor of Philosophy**

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Declaration

I, Jenni Anne Burt, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

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2010

Equity, need and access in health care: a mixed methods investigation of specialist palliative care use in relation to age

The equitable provision of care is a core principle of the NHS. Previous research suggests that older cancer patients may be less likely to use specialist palliative care than younger patients, but studies have failed to fully define and measure clinical need. The aim of this study was to examine use of specialist palliative care in relation to age, after controlling for need. I used a mixed methods approach, grounded in a pragmatic philosophy and drawing upon a health capability account of equitable healthcare.

I undertook a focused ethnography of three specialist palliative care services, using documentary evidence, observation of meetings, and interviews to investigate conceptualisations of need for care. I derived two models of need. The first 'aspirational' model encompassed physical, psychological, social and spiritual care for patients and carers. However, with limited resources, a predominantly physical model of need was applied. Additionally, observations suggested that care may vary in relation to patient characteristics including age.

To locate a suitable measure of need, I conducted a systematic literature review and critical and content appraisal of health-related quality of life instruments. I chose the EORTC QLQ-C30 instrument as the indicator of need in a cross-sectional survey of patients and carers, conducted to measure use of specialist palliative care in relation to age. 252 patients and 137 carers attending four outpatient lung cancer clinics participated. 39% received

specialist palliative care. Age was not associated with use of specialist palliative care; metastatic disease, global quality of life ('need') and the clinic where treatment was provided were.

These findings suggest equitable use of specialist palliative care. However, a comprehensive account of equity must consider both use and quality of care. There were some suggestions that, within a resource-limited context, the quality of care may vary. Future equity research should prospectively consider variations in use and quality of specialist palliative care for different patient groups across all care settings, and from diagnosis to death.

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List of abbreviations

CNS	Clinical Nurse Specialist
COPD	Chronic Obstructive Pulmonary Disease
HRQL	Health related quality of life
ICC	Intraclass Correlation Coefficient
IMD	Index of Multiple Deprivation
IMD	Index of Multiple Deprivation
LRT	Likelihood Ratio Tests
MRC	Medical Research Council
NCPC	National Council of Palliative Care
NHS	National Health Service
NICE	National Institute of Health and Clinical Excellence
NSCLC	Non small cell lung cancer
NSF	National Service Framework
NSF	National Service Framework
NS-SEC	National Statistics Socio-Economic Classification
PCT	Primary Care Trust
QALY	Quality Adjusted Life Years
RCI	Response Consistency Index
RCT	Randomised Controlled Trial
SCLC	Small cell lung cancer
SMR	Standardised Mortality Ratio
SOA	Super Output Area
SPC	Specialist palliative care
SPR	Specialist Registrar
SRR	Standardised Registration Ratio
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Preface

Life is forever changed and very different following a sudden loss.

Kirsti A. Dyer, MD, MS

As many before me have stated, a PhD is a personal journey. As we travel we gain new knowledge and insights, and encounter challenges and difficulties. During this journey, the personal and the professional inevitably impress upon each other. This is particularly the case when challenges are severe.

In 2006, mid-way (I thought) through my PhD, a series of events combined to result in a period of compassionate leave from work. The family illnesses and multiple bereavements I experienced within a short space of time made it particularly difficult to continue within a cancer and palliative care environment. As a result, I was forced to reconsider my plans for the study, and accept a reduction in its aims and scope. I interrupted my recruitment of lung cancer patients and carers for the cross-sectional survey, and was not able to undertake interviews with patients and referrers to specialist palliative care.

Thus, this PhD was created during a particularly testing time. My thinking on aspects of care, and experiences of loss, changed my outlook and my way of working. I hope I came to a deeper understanding of issues as a result of this awareness. I hope, too, that overall it is a better piece of work for this.

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This study would not, of course, have been possible without its participants. Firstly, I would like to thank all those patients and carers who so gracefully agreed to give me their attention and help at a difficult time. Staff at participating specialist palliative care providers endured my repeated attendance at their meetings with good humour and fortitude, responding politely and illuminatingly to my many questions on 'why things were'. My thanks also go to the lung cancer clinic staff who so willingly accommodated me and helped me in my work.

My supervisor, Professor Rosalind Raine, has been a constant source of inspiration, support and challenge. I have benefitted greatly from her time and thoughts, and hope the completion of this thesis represents only the start of our ongoing working relationship. Dr Hilary Plant has also been instrumental in the design and conduct of this study, and in supporting me successfully through to its conclusion. Others have also generously given their expertise: Dr Rumana Omar, Matthew Hotopf, Chris Bonell, Cathy Shipman, Julia-Addington Hall, and Irene Higginson, amongst others.

To Al, Oralie, Sis and Ian, Dad and Jane, Carrie and Andy and many other family, friends and colleagues, thank you. Mum, this is for you.

Chapter 1

Introduction

The appointed day, 5 July 1948, brought not one extra doctor or nurse. What it did was change the way in which people could obtain and pay for care. They ceased to pay for medical attention when they needed it, and paid instead, as taxpayers, collectively. The NHS improved accessibility and distributed what there was more fairly. It made rational development possible, for the hierarchical system of command and control enabled the examination of issues such as equity.

Geoffrey Rivett. From Cradle to Grave: fifty years of the NHS. ¹

The equitable provision of care was a founding principle of the National Health Service (NHS). Its creation was intended to enable access to high quality medical care for all, according to their need. ² Today, the allocation of health care on the basis of clinical need alone remains a central tenet of the service. As the NHS Plan states:

Everyone – no matter how much they earn, who they are, how old they are, where they come from or where they live – should have the health care they need for themselves and for their families. ³

The principle of equitable care is further reinforced in the NHS Constitution for England. The first principle of the Constitution declares that the NHS will provide a comprehensive service to all, regardless of their socioeconomic characteristics, gender, ethnicity, disability, age, sexual orientation, religion or belief. ⁴ The rights of patients recorded within this document include the right to access NHS services, and the right not to be unlawfully discriminated against in the provision of care, including on the basis of age. ⁴

The pursuit of equitable health care is founded on the Government's commitment to principles of social justice. Social justice is concerned with the fair distribution of goods and resources within society, frequently aligned to egalitarian goals. The current Government argues that equality is both a right and a necessity; that 'fairness is the foundation for individual rights, a prosperous economy and a peaceful society.'⁵ However, recent Government health care policy also prioritises the needs of the most disadvantaged in society in their pursuit of reductions in inequalities in health.⁶ The Government's notion of fairness may thus incorporate both egalitarian and prioritarian ideals.

This dual concern, to ensure equality as well as reduce disadvantage within society, is reflected in recent Government efforts to improve the treatment of older people within the NHS. Acknowledging gaps in treatment between older and younger patients, and the deprivation suffered by many people as a result of older age, in 2001 the Government published the National Service Framework (NSF) for Older People.⁷ This aimed to provide a cohesive strategy for the delivery of high quality health care to older people, and outlined steps to tackle age discrimination throughout the NHS. Standard one of the NSF stated that 'NHS services will be provided, regardless of age, on the basis of clinical need alone'.⁷ A 2006 review of the impact of the NSF concluded that, whilst explicit age discrimination in access to NHS services had declined, ageist attitudes and practices persisted.⁸ A more recent report into the treatment of older people within health and social care reinforced these findings, suggesting that action was still required to address implicit discrimination and negative attitudes.⁹

Cancer care is one of several clinical areas where concerns about inequitable use of services by age have arisen. Cancer is predominantly a disease of

older people; in 2006, two thirds of cancers and three quarters of cancer deaths occurred in people aged 65 and over.¹⁰ Lower use of cancer services by older people has been reported along the entire disease course, from diagnosis through to treatment and supportive care.^{11;12} The NHS Cancer Plan and the more recent Cancer Reform Strategy acknowledged that there were variations in the treatment patients received according to their age, and stated that such variations were unacceptable.^{13;14}

Current evidence suggests inequalities in access to and use of cancer care persist up until death. Systematic reviews of palliative care use have concluded that older patients are less likely to receive these services compared to their younger counterparts.¹⁵⁻¹⁷ The NSF for Older People highlighted concerns that older people may have more limited access to palliative care.⁷ This policy message was reinforced by the publication of a World Health Organisation (WHO) report on palliative care for older people, which suggested that older age may be a barrier to end of life care.¹⁸

Alongside their cancer care reform programme, the Government have aimed to improve the funding and provision of palliative care services. Publication of guidance on supportive and palliative care by the National Institute for Clinical Excellence (NICE) in 2004 was followed by the End of Life Care Strategy in 2008.^{19;20} Under this strategy, PCTs are required to conduct a comprehensive assessment of the end of life care needs of their population, with a particular aim of providing high quality care to all regardless of age and other patient characteristics.

Current policy thus strongly supports efforts to ensure older people receive the health care they need, including end of life care. Efforts to reduce acknowledged variations in access as a result of age will be further

reinforced by the introduction of the Equality Bill currently before Parliament.²¹ The Equality Bill would explicitly ban age discrimination against adults in the provision of goods, facilities and services. This would legally require the same medical care to be given to people with the same condition, regardless of age, unless age-based variations in care were justifiable.

However, the Government has acknowledged that further methodological developments and research are required to develop understanding of inequities in access to health care. As a result, it has established a National Cancer Equality Initiative to advise on future research, and to develop an action plan to reduce inequalities in cancer care. Research into the fair distribution of healthcare is dependent on a number of important factors. The first of these is the accurate definition and measurement of need.²² This is essential if we are to assess equity (variations in use between groups which cannot be attributed to variations in need) rather than simply equality of use.²³ There are a number of different approaches to defining need for healthcare, but within public health, need for health care is commonly classified as a person's capacity to benefit from that health care.^{24,25} This may encompass not just physical, but social, emotional and other outcomes.²⁶ Such holistic approaches to need measurement may be particularly relevant to palliative care, which aims to improve quality of life across all its dimensions.²⁷

To date, studies on variations in use of palliative care have not comprehensively investigated and controlled for patients' need for care. Typically, studies have looked at use without considering need, or have approximated need to the existence of a cancer diagnosis or the presence of a physical symptom such as pain.¹⁵ Furthermore, studies have rarely considered the needs of carers as well as patients in determining use of care,

in spite of the stated aim of palliative care to improve quality of life for patients *and their families*.²⁷ Definitions of palliative care need are complicated by the division of palliative care into that that provided by generalists in their everyday work (such as GPs and district nurses), and that provided by specialists (such as consultants and clinical nurse specialists in palliative medicine).²⁸ In this model, specialists offer advice and care to patients with more complex and persistent problems, which generalists may not have the skills to deal with effectively.¹⁹ However, there is currently little evidence on how providers distinguish a need for specialist as opposed to generalist palliative care.

Accurate data on use are also essential if we are to draw firm conclusions about the distribution of health care. Previous studies of the use of palliative care have often drawn on incomplete and inaccurate data on use, in part as most have taken a retrospective approach. Cross-sectional and prospective methods offer a more rigorous way of gathering high quality data on service referral and use.

A comprehensive investigation into health care inequalities will thus define, operationalise and accurately measure need in relation to use, as well as considering the reasons why any variations in use arise. Mixed methods represent a particularly suitable approach to achieving this, combining qualitative and quantitative techniques to formulate and measure concepts of need for care and assess access in relation to this need. Mixed methods are frequently partnered by a pragmatic philosophy, particular concerns of which are the clarification of ideas through consideration of their practical consequences, and the acknowledgement of the influence of the beliefs of the researcher on the matter at hand.²⁹ Such ideas are particularly relevant to research into inequalities, which may stem from a belief that differences in

the use of health care which do not reflect differences in need are unjust, and must be reduced.

The aim of this study is to examine use of specialist palliative care (SPC) services, in relation to age, after controlling for need. There are three core objectives:

1. To explore, using documentary evidence, qualitative observation and interviews, how SPC providers define and conceptualise patients' need for care.
2. To systematically identify health-related quality of life (HRQL) instruments developed for use in palliative care and lung cancer patient populations, and to appraise their validity for use as indicators of need for SPC.
3. To conduct a cross-sectional survey to measure use of SPC in younger versus older lung cancer patients, in relation to need.

I start the thesis with an overview of relevant conceptual issues, including theories of social justice, equity and need; current evidence of use of SPC by age; and potential explanations for variations in the use of health care in older people. I then consider theoretical and methodological issues in mixed methods research, giving a detailed account of the development and structure of this study including its grounding in a pragmatic approach. The background sections of the thesis close with a detailed description of the context and setting of the study, including further details of the nature of palliative and lung cancer care. Descriptions of the empirical work undertaken then commence with my ethnographic study of three SPC

providers to consider how need for care may be conceptualised. I move on to present the methods and findings of a systematic literature review and critical appraisal of existing HRQL instruments used within cancer and palliative care, and their relevance for use as indicators of need. The final empirical work presented is a cross-sectional survey of lung cancer patients and carers assessing use of SPC in relation to age, after controlling for need. In the closing chapter, I draw these elements together to present inferences derived from this research, my conclusions, and my recommendations for further research and future policy developments.

Chapter 2

Conceptual overview

*Youth is full of sport,
Age's breath is short,
Youth is nimble, Age is lame:
Youth is hot and bold,
Age is weak and cold.*

William Shakespeare. From *The Passionate Pilgrim*.³⁰

Current Government policy supports equal access to SPC regardless of age. Why is this? What principles are used to determine the distribution of health care? Further, if differences between older and younger people in the use of SPC are seen as unfair, how might such differences arise?

In this chapter I outline concepts of social justice, equity and need for health care, although I reserve further analysis of these accounts for my conclusions. I consider issues in defining and measuring need for SPC, and current evidence for variations of use of SPC by age. Finally, I present explanations for lower use of SPC by older patients.

2.1 Social justice, equity and need

The NHS was founded to be universally available, comprehensive and free at the point of use.³¹ The concept of a publicly financed health care system, available to all on the basis of clinical need rather than ability to pay, was revolutionary at the time.³² Despite major reorganisations and changes over the years, most notably the more recent introduction of the principles of patient choice and provider competition, the founding principles of the NHS

remain strong.³³ The current Government recently reaffirmed its commitment to these, set out in a new NHS Constitution published in 2008 following Lord Darzi's Next Stage Review.^{4;34} The Constitution sets out seven core principles of the NHS, which include access on the basis of clinical need, and the provision of a comprehensive service available to all. These principles are underpinned by core values, including respect and dignity, commitment to quality of care, and compassion.

Social justice and health care

The UK Government's adherence to equitable principles within health care stems from an ongoing commitment to social justice. Theories of social justice are concerned with how goods and resources are shared amongst members of society. Philosophical debates about which principles of distributional justice should guide access to health care underpin the public health literature on equity of care, and thus are reviewed briefly below.

The most influential theory of social justice, 'Justice as Fairness,' was proposed by John Rawls in 1971.³⁵ In his theory, he argues that rational persons would choose two general principles of justice to structure society:

1. *Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.*
2. *Social and economic inequalities are to be arranged so that they are both: [2a] to be attached to offices and positions open to all under conditions of fair equality of opportunity; [2b] and to be to the greatest benefit of the least advantaged members of society (the difference principle).³⁶ p266*

The first principle has priority over the second principle, whilst within the second principle, the principle of fair equality of opportunity (2a) takes precedence over the difference principle (2b). A person's advantage

(essential to applications of the difference principle) is defined by social primary goods, which Rawls classifies into five groups:

- (a) basic rights and liberties;*
- (b) freedom of movement and choice of occupation;*
- (c) powers and prerogatives of offices and positions of authority and responsibility;*
- (d. income and wealth;*
- (e) the social bases of self-respect. ³⁶ p386*

Rawls did not explicitly include health or health care as one of the basic social goods which should be distributed equally. However, the influence of Rawlsian arguments is such that they have subsequently been applied to health care, albeit in different ways. ^{37;38} Philosopher Norman Daniels extended Rawls' 'fair equality of opportunity' principle (his second principle) to decisions about the distribution of health care. He argues that the primary function of health care is to maintain normal species functioning, and thus the range of opportunities that are open to individuals. The achievement of this principle requires universal access to appropriate health care, not based on ability to pay. ³⁷ However, Daniels also acknowledges that health care is not the only social good to be distributed, and so in his formulation of justice rationing and prioritisation are inevitable. ³⁹ This includes the restriction of health care in some circumstances to older patients. Ethicist Ronald Green, by contrast, draws on Rawls' first principle of justice to support his argument that health care is one of the basic social goods. ⁴⁰ He contends that access to health care is instrumental to the pursuit of other values held to be important, and that there is a right of equal access to the best quality health care that a society can afford. ⁴¹ These and other approaches to the distribution of health care are summarised in Figure 2.1.

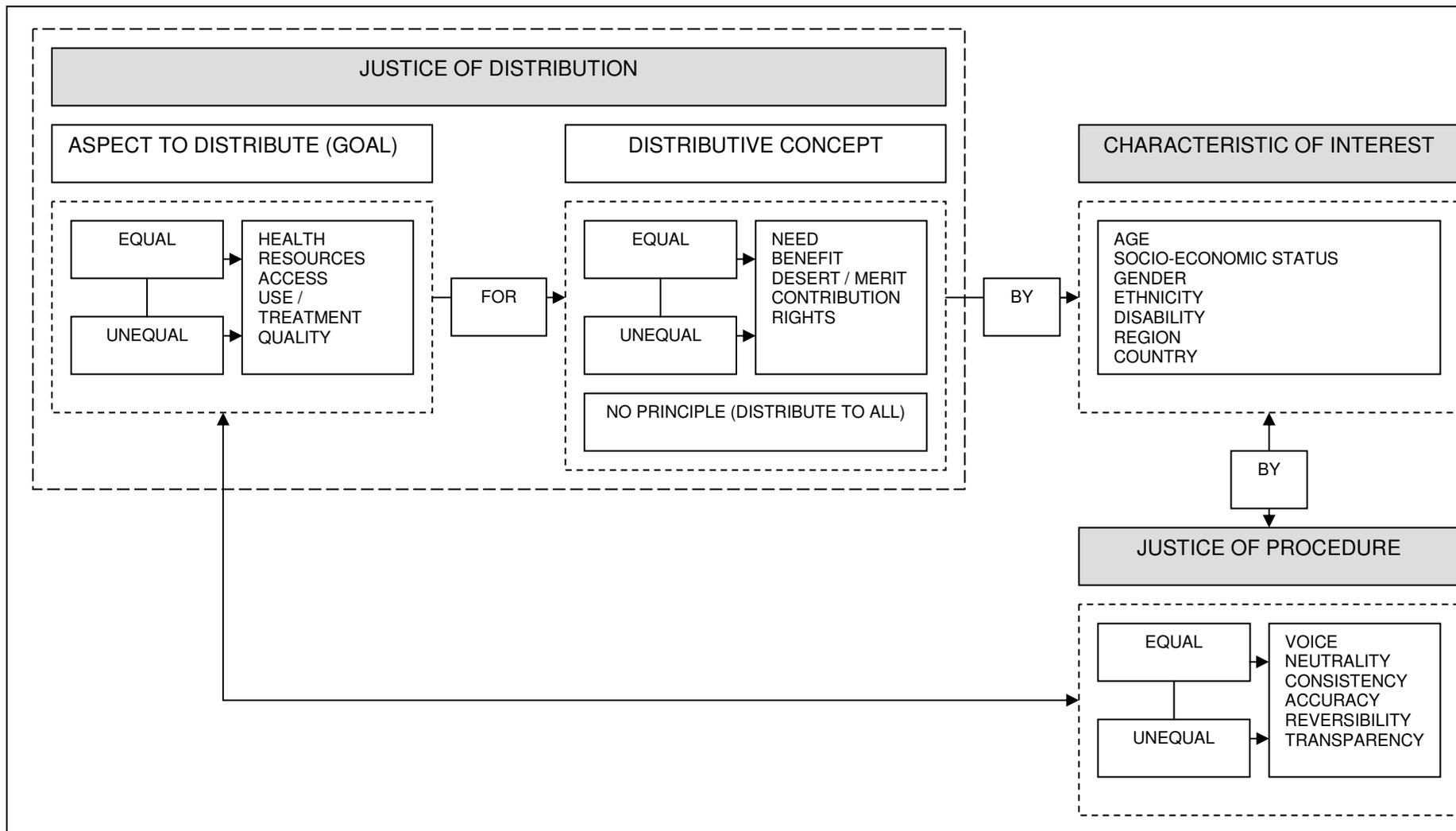


Figure 2.1 Distributive and procedural justice and health care

Rawlsian principles of social justice have been criticised by proponents of the capability approach. In particular, Amartya Sen argues that the use of primary social goods to identify advantage or disadvantage is insufficient to account for differences between people, and in particular people's abilities to convert primary goods into what they wish to be and to do with their lives. We should instead focus on people's capabilities to function.⁴² Capabilities represent different combinations of functionings (doing and being) with resources (that which are used to achieve functionings). Sen himself has refrained from defining what these capabilities are, but another influential capability theorist, Martha Nussbaum, has committed herself to providing a list.⁴³ This comprises ten capabilities which she argues are essential for a good life, and which capability-based theories of social justice should promote:

1. normal life span
2. bodily health
3. bodily integrity
4. senses imagination and thought
5. emotions
6. practical reason
7. affiliation
8. other species
9. play
10. control over one's environment

Whilst, as with Rawls, capability approaches did not at first directly include health, their influence has spread to the debate about the distribution of health care.⁴⁴ Sen has set out the centrality of illness and health to any

discussion of social justice and equity, and argued for a multidimensional concept of health equity.⁴⁵ This is concerned with:

*...the achievement of health and the capability to achieve good health, not just the distribution of health care. But it also includes the fairness of process and thus must attach importance to non-discrimination in the delivery of health care.*⁴⁵ p31

Ruger has further developed a capability view of health and access to health care (the 'health capability account') and outlined its implications for public health policy.⁴⁶⁻⁴⁸ In her theoretical framework, health policy should aim to support individual's capabilities for health functioning by providing the conditions in which individuals can meet their health needs.⁴⁶ The goal of health systems is to reduce disparities in health capabilities in the most efficient manner. This should be achieved through both procedural mechanisms and by reference to a substantive, capability approach with its focus on removing barriers to both process and opportunity aspects of freedom. Aiming for equal access to high quality evidence-based care, making efforts to expand individual's health agency (their ability to navigate the health care system), and taking a shared responsibility between individuals, providers and institutions to achieve health goals all stem from this approach.⁴⁶ Further, Ruger argues for the moral importance of health care quality, as differences in the quality of health care available to individuals are unjust in their impact on individual's capability for health functioning.⁴⁸ A final dimension of Ruger's theoretical argument for equal access to health care is the requirement for society to seek to remove any social disadvantages (including reduced access to health care) that may result from social exclusion.⁴⁸ Thus, social norms towards, for example, older adults, must be inclusive, ensure dignity and grant each individual equal moral worth.⁴⁸

The major distinction between Rawlsian and capability approaches is that the former emphasises outcomes, whereas the latter emphasises the means to achieve outcomes. Thus, Sen argues for a focus on the ability of people to choose between opportunities, whereas Rawlsian approaches (including that of Daniels) are focused on the opportunities themselves. As Sen writes:

Equality of freedom to pursue our ends cannot be generated by equality in the distribution of primary goods. We have to examine interpersonal variations in the transformation of primary goods (and resources more generally) into respective capabilities to pursue our ends and objectives. ⁴⁹ p87

The concepts of social justice outlined above are predominantly egalitarian. None are strictly egalitarian. This would require all health care to be distributed equally, regardless of whether this forces everyone to be worse off than they may have been in an unequal society (an outcome known as 'levelling down'). ⁵⁰ Instead, conditional egalitarianism incorporates efficiency principles alongside egalitarian principles. Thus, under Rawls' difference principle, an expansion of inequality may be just as long as it is not detrimental to the less advantaged. Such an outcome is known as a Pareto improvement: a distributional decision which makes one individual better off without making any other individual worse off.

There are further, alternative formulations of social justice, primarily based either on prioritarian or on sufficiency principles. ⁵¹ Prioritarian principles, such as those set out by Derek Parfit, are founded on the argument that improving the position of the worst off is of greater importance than achieving equality. ⁵² Whilst both prioritarians and egalitarians might support the moral importance of benefitting the worst off, Parfit asserts that these concerns arise from differing underlying beliefs. Thus, he argues that an egalitarian is concerned with relative wellbeing, whilst a prioritarian is

concerned with absolute wellbeing.⁵² His view is a variation of utilitarianism, in that improving the situation of the most deprived will bring about the greatest gain in social utility or well-being.

By contrast, sufficiency principles question whether everyone has 'enough', and are concerned with maintaining people above a critical threshold of advantage.^{53;54} Casal identifies two formulations of the sufficiency thesis.⁵¹ In its positive and moderate form, sufficiency is simply concerned with eliminating deprivation, a widely supported goal which is compatible with additional distributional principles. By contrast, the negative formulation of sufficientarianism focuses entirely on ensuring that everyone has enough, and explicitly rejects egalitarian and prioritarian principles. Thus, as long as everyone has reached the threshold of sufficiency, it is seen as of no moral importance if others have more.⁵³ As Crisp states:

*The Compassion Principle: absolute priority is to be given to benefits to those below the threshold at which compassion enters. Below the threshold, benefiting people matters more the worse off those people are, the more of those people there are, and the greater the size of the benefit in question. Above the threshold, or in cases concerning only trivial benefits below the threshold, no priority is to be given.*⁵⁴

There is a lively, ongoing debate within the philosophical literature about the detail, respective merits, and compatibility of egalitarianism, prioritarianism and sufficientism (see for example Campbell Brown⁵⁵ and Ole Norheim⁵⁶). Thus, principles of social justice underpinning health care provision remain contested, with no clear consensus emerging. For this reason, Daniels has argued that in the absence of agreement on guiding principles of distribution, a focus on procedural principles is increasingly important [see Figure 2.1, page 26, for an illustration of these].³⁹ As he states:

Access to health care cannot be considered equitable if it is much more difficult for some people to get care than it is for others, even if people make adjustments to the burdensomeness of the process and get the amount of care they need. ⁵⁷

His formulation, together with Jim Sabin, of 'accountability for reasonableness' sets four conditions to ensure fairness in setting priorities for health care, and places procedural rather than distributional justice at the heart of the debate: ⁵⁸

- Relevance – evidence and values used to make priority setting decisions must be relevant
- Publicity – priority setting decisions and the reasons behind them must be made public and accessible
- Revisability – decisions must be reviewed in the light of new evidence and public opinion
- Enforcement – the above conditions must be met

Philosophical criticisms of the accountability for reasonableness approach centre on the lack of clarity about which criterion of 'fairness' Daniels is appealing to. ⁵⁹ Additionally, Ruger has argued that this emphasis on fair procedures may allow differential access to health care between different areas or health plans as long as each has satisfied the conditions for accountability for reasonableness, a situation a capability approach would not support. ⁴⁸ Practical criticisms highlight the fact that the authors have not suggested how institutions might actually operationalise the model. ⁶⁰

Some of this criticism reflects a wider concern that philosophical debates on justice take place at an abstract level which renders their application to practical policy making decisions almost unworkable. ⁶¹ This has been taken up by philosophers Jonathan Wolff and Avner de-Shalit, who set out to

formulate an egalitarian theory which was applicable to social policy. They argue that the crucial issue facing governments, in the light of restricted resources, is simply 'to identify the worst off and take appropriate steps so that their position can be improved'.⁶² p3 They acknowledge the importance of both distributional and social equality, but aim to weave these together to provide a model to guide the relief of disadvantage. In doing so, they draw on the capability approach of Sen and Nussbaum. Using this as a springboard, the major modification they propose is that what matters to an individual is not only the level of functionings they have at any particular point, but their likelihood of sustaining that level of functioning. They summarise their overall proposition as follows:

*...the interaction of your internal resources and your external resources with the social and material structure within which you find yourself, determines your genuine opportunities for secure functionings, creating for you paths of varying cost and difficulty. In short, your resources are what you have to play with; the structure provides the rules of the game.*⁶² p 173

Opportunities for addressing disadvantage therefore exist at the level of internal resources (including medical intervention), external resources (including cash compensation or resource enhancement) and social structures (including changes in the law or social attitudes).⁶² In the formulation of Government policy, according to Wolff and de Shalit, priority should be given to the least advantaged: however, this does not mean that the least advantaged will *always* receive priority. Thus, if doctors must decide between offering a heart transplant to one of two patients, they are still likely to decide the recipient on the basis of clinical norms rather than purely on the basis of which patient is the least educated or otherwise disadvantaged. Whether the hospital receives sufficient resources in the first place to offer heart transplants will, however, be in part decided by whether

this is a component of an efficient package of measures aimed at improving the position of the least advantaged overall.

As Wolff and de-Shalit recognise, the importance attached to social justice by the Government demands that decisions *are* made about how best to offer a system of health care regarded by society as fair (and, typically, equitable). I therefore turn now to consider the definition of equity within health care theory and policy.

Equity of health care

In 1992, Margaret Whitehead published an influential paper on equity and health that defined health inequities as differences in health which were unnecessary, unfair and unjust.²³ She went on to offer three possible definitions of equity in health care:

1. Equal access to available care for equal need
2. Equal use for equal need
3. Equal quality of care for all

The distinction between equity and equality is important: equity, unlike equality, is essentially a normative concept.⁶³ Not all health care inequalities may be judged to be unjust or unfair – however, Whitehead does not go on to specify how such judgements should be made.⁶⁴

The distinction between access and use emphasised by Whitehead is also an important one.^{65;66} Access is concerned with the availability of suitable opportunities to use health care. Whether individuals and groups actually gain access to (use) the health care services they need depends on issues such as the affordability, physical accessibility and acceptability of services, not

just the sufficiency of supply.⁶⁷ The opportunity to use health care may thus not be converted into actual use, whether for social, cultural, practical, attitudinal or other reasons. Differences in use which arise as a result of differences in individual preferences are unlikely to be regarded as inequitable, although the attribution of use to individual choice or other factors external to an individual is difficult.⁶⁸ Access to health care is perhaps a more conceptually important measure than use of health care, as it is the equal opportunity to use health care that is the central concern of health care systems pursuit of equity, even if that opportunity is not taken up.²⁶ However, in practice, use is the measure that is employed by most researchers, for the simple reason that it is more easily determined.⁶⁹

Whitehead's third definition of equity of health care, that of quality, moves away from outcomes to consider the nature of care provided. Systematic differences between particular groups of people in the speed with which they receive care, the quantity or intensity of the care received, and the humanity with which care is delivered may all therefore be aspects of inequity of care. Thus, it is not only entry into the health care system which must be monitored if we are concerned about the achievement of equity, but also what occurs as people travel through the system. This again highlights the importance of procedural justice; whilst we may accept the outcome of the chosen distributional principle, concerns could remain if the process by which these outcomes are achieved is considered unfair. Thus, as outlined above, Norman Daniels has argued that access to health care cannot be seen as equitable if it is more difficult for some people to get that care, even if they are adequately treated in the end.⁵⁷ Sen has also reiterated the importance of process equity, alongside outcomes (such as improved health) and the capability to achieve these outcomes.⁴⁵

There are two important dimensions of equity, originating in Aristotelian theories of justice. The first principle, known as horizontal equity, requires the equal treatment of individuals who are equal in relevant respects (for example, there should be equal use for equal need). The second, related principle requires the proportionately unequal treatment of individuals unequal in relevant respects (for example, unequal use for unequal need). This is known as vertical equity. A comprehensive examination of equity of health care will incorporate both measures, as the presence of horizontal equity does not necessarily imply the presence of vertical equity.⁷⁰ For example, whilst both older and younger cancer patients with an advanced stage of disease may be equally likely to receive a particular course of treatment, it does not necessarily follow that there is equal access to treatment by age group at a less advanced stage of cancer.

A slightly different perspective on vertical equity is given by economist Gavin Mooney, who argues that vertical equity is essentially about positive discrimination.⁷¹ Acknowledging that, thus far, a concern with delivering equitable health care has done little to narrow the gap between the advantaged and disadvantaged, Mooney suggests a community approach to deciding the relevant claims on care of each social group.⁷² Consequences of care (such as an improvement in health) may be less important than the process by which care is decided.⁷¹ Mooney's work moves the concept of vertical equity away from egalitarian principles and towards prioritarian principles. Although not explicitly stated, it is apparent that in his support of efforts to provide fairer health care by reducing differences in health, access to and use of health care, the underlying concern becomes not relative wellbeing, but absolute wellbeing.

Whilst both dimensions of equity are important if assessments are to be comprehensive, in research practice to date the focus has predominantly been on horizontal equity.⁷³ This is most commonly defined as 'equal use for equal need'.⁶⁹ If this is the case, the question arises as to what is meant by need.

Need for health care

The nature of need has been the subject of much debate. I do not intend to present an extensive summary of the literature on human need, but a diversion into aspects of this debate is presented as a foundation to ideas of need for health care.

At its most fundamental, the argument on the nature of human needs centres on whether these may be classified as objective and irrefutable, or subjective and contestable.⁷⁴ Abraham Maslow's influential hierarchy of human needs defines 'basic needs' which must be fulfilled in pursuit of the ultimate goal of self-actualisation. Arguing for the universality of these needs, Maslow stipulates that the fulfilment of these basic needs is a necessary prerequisite for health.⁷⁵ Similar formulations in relation to health needs include that of Doyal and Gough, who define physical health as a basic, and objective, need which must be met to fully participate in social life.⁷⁶

If 'true needs' exist, it follows that they may be distinguished from 'false needs'.⁷⁴ However, the determination of both true and false needs on an empirical basis alone is criticised by those who argue that value judgements are involved in the definition of needs.⁷⁷ If this is the case, it is the current social and political context which will influence which needs are judged as legitimate.⁷⁴

Below, I review four major approaches to defining health care need, as categorised by a philosopher, Per-Erik Liss.⁷⁸ The four groups defined by Liss are ill health; supply; normative; and instrumental.

Donabedian's ill health notion of need is that a need for health care exists when there are some deficiencies in health that require health care.⁷⁹ A criticism of this perspective is that a person's need for health care should in fact depend on the existence of an effective or acceptable treatment for that person's illness or disability. That is, a person cannot need health care if there is no service or technology available to improve their health. In this situation, a person may have a need for health, but they do not have a need for health care.⁷⁰ This perspective forms the basis of the supply notion of need for health care: a need exists when there are both deficiencies in health and an effective treatment available. Acheson added to this approach by arguing that definitions must account for the limited availability of resources, arguing that a need exists only when effective interventions can be provided 'at reasonable cost'.^{80;81}

Normative notions of need stress that there is a need when someone (for example, a patient, or a doctor) believes that health care should be provided to an individual or population. In such formulations, medical professionals are typically identified as the ones to decide 'objective' health care needs. These needs are then contrasted with 'wants' or 'demands', reflecting the health care individuals or the public at large feel they ought to receive (correctly or otherwise).^{82;83} Magi and Allender recognised the unequal power balance between doctors and patients in determining need under such approaches. They argued that both perceived need (from an individual's perspective) and medically defined need (from a doctor's perspective) incorporate values and norms.⁸⁴

Bradshaw's influential taxonomy of social need, widely used within social policy, includes the concept of normative need.⁸⁵ He defines 'normative need' as that decided by a group of experts, reflecting the 'desirable condition' within that society. As such, normative need is based entirely on value judgements and will change with changing social values. Three other components of need make up Bradshaw's concept of 'total need': felt need (as experienced by individuals), expressed need (felt need which is acted upon or demand) and comparative need (based on comparing groups or individuals within a population).⁸⁵

Finally, instrumental notions of need for health care suggest that health care is necessary to achieve a particular end state, such as 'health'.^{25;57;86}

Instrumental approaches derived from health economics additionally introduce ideas of efficiency to the concept of need alongside an examination of the change in state as the result of an intervention.

It is an instrumental definition of need for health care that has come to dominate current public health thinking and research. This is economist Tony Culyer's formulation of need for health care as 'capacity to benefit' from that health care.²⁵ In practice, capacity to benefit is often equated to health status. Thus, in epidemiologically based needs assessments used to inform decisions about expenditure within a health system, data are gathered on disease burden and cost effectiveness to measure need for care.

⁸⁷ This approach separates out need from demand (what people might be willing to pay for, or wish to use in a system of free health care), and from supply (what is actually provided).⁸⁸ Further, need tends to be categorised into a dichotomy of need/no need, or into groups representing different levels of need, rather than conceived as a continuum.

Culyer's formulation follows supply notions of need in requiring that health care must be effective for a need to exist: if there is no expected health gain, there can be no capacity to benefit. Benefits may be drawn widely and encompass social, emotional and other outcomes.²⁶ However, as Culyer himself has demonstrated, the application of 'capacity to benefit' alone as a definition of need may lead to difficulties in the equitable distribution of care.²⁴ Thus, in his later work, Culyer refined his formula to include resources:

*A need for health care is the minimum amount of resources required to exhaust a person's capacity to benefit.*²⁴

He argues that this definition incorporates essential aspects of need in that it is instrumental, with a moral objective (Culyer states this to be 'health for flourishing'), sets out what is needed (resources), and additionally defines the amount required (that which will exhaust capacity to benefit) without setting limits to this.⁸⁸

Culyer's influential formulation of need, with its focus on quantitative approaches to assessment, has been criticised for excluding consideration of human behaviour (see e.g. James 1999⁸⁹). This criticism may be particularly relevant to health care specialties such as SPC, where decisions about relative need involve assessment over multiple domains. Purely quantitative approaches risk excluding the complexities of individual behaviour, social circumstances and cultural norms from approaches to defining and assessing need. Furthermore, they do not identify or provide a value framework through which consensus may be sought as to which needs are accepted as needs by society.^{72;89}

Alternative approaches to the formulation of need come from the emerging sociological literature on micro-rationing.⁹⁰ For example, research into the acceptance of patients for cardiac surgery and neuro-rehabilitation found clinical decisions were influenced by implicit moral concepts of 'deservingness' rather than clinical ability to benefit, with age, smoking habits, and other social factors appearing to affect admission to care.⁹¹ In making such decisions, staff moved from a 'technical' to a 'social' discourse when a characteristic such as the older age of a patient came into focus, with attitudes displayed reflecting those of the wider public.⁹²

Further, observations of mental health team meeting discussions have found that, for all patients regardless of age, rationing of care was more likely to take place by reducing the intensity of treatment on offer, delaying access to care or re-defining cases as inappropriate, rather than explicitly refusing access.⁹³ This highlights the importance of considering 'need' as a continuum rather than the more typical dichotomy of present/absent suggested by economic formulations.

Whether formulations of need are derived from an economic or sociological stance, the crucial point is that any study of health care use explicitly defines and operationalises a model of need. Goddard and Smith list a number of key assumptions often made when investigating the use of health care.²⁶ Firstly, studies have disregarded need completely, equivalent to assuming that levels of need are the same in each patient group being studied. Secondly, studies have assumed that morbidity may suffice as a measure of need, without investigation as to whether this is sufficiently comprehensive for the service under study. Finally, studies have assumed area-level characteristics can be applied to individuals as a proxy of their need.²⁶ The practice of most studies which do consider ability to benefit is to rely on the

measurement of individual health status, which may be an incomplete measure of need for some health care.

Furthermore, capacity to benefit – the most commonly used definition of need within public health – may vary in relation to individual characteristics such as age, diagnosis, prognosis, comorbidity, family support, living conditions, socio-economic status, religious/spiritual beliefs, and access to other services. All these may therefore be relevant when considering variations in the use of health care. If Culyer's definition of need is to be strictly applied, questions also arise about the measurement of resources. For example, should resources be measured cross-sectionally or longitudinally when considering need for care? That is, do early presenters to health care have a greater need (requirement for resources to reduce their capacity to benefit to zero) than late presenters? Time may have a varying influence depending on the health problem of concern. Furthermore, Culyer's approach requires services to be effective in order for them to be needed. This leads to the question of whether there are particular situations or patient characteristics which make services more effective, and if this is the case, what the implications of this are for the level of need.

Approaches to the definition and measurement of need are, as highlighted above, varied and contested. Inevitably, the requirement for quantitative needs assessment in research and planning means that the complexities of how need is conceived and shaped within a clinical encounter may be lost in its measurement. However, as Goddard and Smith highlight, studies must at least state their approach to the definition and measurement of need, even if this is acknowledged to be limited. ²⁶

Following this overview of equity and need, I turn to consider how these key concepts have been employed within policy and practice in recent years.

Theory and policy: the current Government's position

Since the election of the Labour Government in May 1997, public health policy and healthcare funding has focused on reducing health inequalities and improving access to health care for disadvantaged groups.⁹⁴ Thus, access to healthcare is explicitly linked to an impact on health inequalities. As the Government reiterated in their 2009 response to the Health Select Committee's report on health inequalities:

*Resource allocation to PCTs is designed to ensure equal access for equal need and help to reduce health inequalities. It aims to target resources to where health care need is greatest.*⁹⁵

The Government's pursuit of better health and better health care for all, and the narrowing or elimination of inequalities, has led to policies specifically targeting disadvantaged areas and groups. In 2004, the Department of Health announced a list of 'Spearhead PCTs' in which they would focus efforts to reduce health inequalities.⁹⁶ These PCTs (currently there are 62) were selected as their populations were in the lowest fifth of local authorities for at least three of the five following measures: life expectancy at birth in males and in females, mortality rates from all circulatory disease and cancer in people aged under 75, and the average score in the Index of Multiple Deprivation 2004. Spearhead PCTs were given additional funding, and a number of national initiatives aimed at reducing health inequalities (such as enhanced stop smoking services) and improving access to health care were piloted in these areas.⁶ Arguing that increasing access to primary care is one of the most effective ways of improving population health, the Government has also

funded additional GP practices in areas identified as lacking in provision and high in disadvantage.⁹⁷

Lord Darzi recently argued that ‘a fair NHS must continue to be equally available to all, taking full account of personal circumstances and diversity.’

⁹⁷ He went on to state:

*To create a fairer NHS, we have to focus on improving access to health and social care services for people in disadvantaged and hard-to-reach groups and those living in deprived areas.*⁹⁷

Thus, in both theory and policy, recent Government approaches to the distribution of care appear to be based both on egalitarian and prioritarian principles. Access to the NHS should be based on equal need, but priority (and thus extra resources) should be given to those in most need. Donald Franklin, economic adviser to the Department of Health, has suggested that current Government policy and practice reflects a pragmatic adaptation of a broadly utilitarian agenda which aims to maximise the net benefit of health care.⁹⁸ Recognising that historical distributions of care have been biased against particular groups, he argues that an efficient approach to maximising utility is to target health care delivery towards the disadvantaged. The result is policies with a concern for health inequalities based on the belief that improving health is a means to increase utility (in this case, by preventing or removing pain and suffering). However, Franklin also identifies inconsistencies within Government rhetoric. He suggests that documents such as *Saving Lives: Our Healthier Nation* outline a broader notion of health, the improvement of which is valued not just its utilitarian good, but also for its capacity to enable us to lead lives of value:

We believe that good health, like good education, should be within reach of all. [...] Better health is vital in itself, leading directly to longer, more active and more fulfilled lives. ⁹⁴

The approach of the current Government echoes Wolff and de-Shalit's argument that targeting the worst off is the only sensible tactic in the face of limited resources. ⁶² However, the doctrine behind Government policies (whether prioritarian, egalitarian, sufficientarian or some combination of the above) is never explicitly stated. Anand has argued that the Government's stance represents a moral hybrid. ⁹⁹ He contrasts the utilitarian approach to priority setting with the prioritisation of patient autonomy and choice at the clinical level, suggesting that this is more reflective of a capabilities approach with its emphasis on the opportunities individuals have. 'Fairness' in practice may thus be concerned with reaching out to those suffering the most, striving to bring everyone over a particular threshold of quality of life, *and* making sure everyone in the same situation gets the same. The challenge is to connect this with a coherent theoretical basis for action.

The concept of vertical equity – unequal use for unequal need – is also particularly relevant to current Government policy. As Mooney argues:

...positive discrimination is needed if health services are to be capable of meeting the call to provide fairer health care in such a manner as to have some impact on the gaps in health, access or use that exist between the better off in societies and the worse off.

⁷¹

The Government concern with narrowing the gap between the advantaged and the disadvantaged may have consequences for the definitions of need they use to make decisions about the allocation of care. If a fundamental health care policy goal is a reduction in health inequalities, this requires an understanding both of the impact of health care on health, and of how best to

target this health care to the greatest benefit of disadvantaged populations.

¹⁰⁰ In deciding resource allocation within health care, this approach may lead the Government away from an explicit commitment to equal access for equal clinical need, towards a commitment to equal access for some concept of equal social need. ¹⁰⁰ That is, preferential access may be offered not simply on the basis of disease severity, but also with consideration of personal characteristics, to target care towards vulnerable groups such as the poor or the old. However, this stance has not yet been explicitly acknowledged by the Government.

Following this consideration of the wider context of equity theory and policy, I move on to look at how these issues apply specifically to specialist palliative care.

2.2 Examining equity of specialist palliative care

Investigations into the fair distribution of health care must account for the nature of the service under investigation. SPC has a number of dimensions which render it particularly interesting for investigations of equity: its provision across multiple settings (at home, in hospitals and hospices), the split between NHS and voluntary providers, and its multidisciplinary nature. Furthermore, SPC makes claims about its holistic nature which may make it challenging to formulate and measure a concept of need for care. Below, I consider how studies have considered need for SPC, and the evidence on use of SPC by age they have generated.

Need for specialist palliative care

To date, studies involving need for SPC have suffered from a number of the limitations outlined by Goddard and Smith. ²⁶ Firstly, studies may not define what need encompasses. For example, one US report on the differences in

palliative care needs in older versus younger patients compared the groups on the basis of diagnosis, recommendations on advance care planning and symptom management, and decisions about withholding or withdrawing treatment, without explaining how these may signify need for care. ¹⁰¹

Alternatively, need for SPC is equated directly with diagnosis. Thus, individuals with the diagnosis of interest, typically cancer, are identified using administrative health data (e.g. ¹⁰²) or reports of bereaved relatives (e.g. ¹⁰³), and their use of SPC analysed in relation to characteristics of interest such as age. This assumes that all individuals with cancer require SPC, which is unlikely to be the case. A small refinement of this approach was employed by Currow et. al., who used a survey of bereaved relatives to obtain data on diagnosis, reported receipt of SPC, usefulness of SPC, and reasons for not receiving SPC. ¹⁰⁴ Use of SPC was then compared to perceived benefit of SPC by patient characteristics including diagnosis and age, and an estimate of unmet need according to these characteristics derived. This assumes that the proportion of individuals with a particular diagnosis estimated by relatives to have found SPC useful represents the proportion of patients who need such care. It is doubtful that measuring perceived usefulness is equivalent to measuring capacity to benefit.

Patient surveys of groups including advanced cancer patients are another approach used to measure need for SPC. Such surveys tend to use much more comprehensive formulations of need, questioning respondents on prevalence and intensity across areas including physical symptoms, emotional, psychological and social problems, and activities of daily living. ^{105;106} However, full psychometric testing of the instruments used in these surveys has not been undertaken. Thus, whilst their content validity may be high, reliability is unknown. Another study used interviews with advanced

cancer patients already under the care of SPC teams to identify eleven needs over five areas: psychological (emotional support, self-fulfilment, emotional closeness, communication, occupational functioning), health related (symptom control, nutrition, and sleep), instrumental (personal care), financial, and informational.¹⁰⁷

Surveys of health care professionals have also been used to identify patients who have a need for SPC. Gott and colleagues conducted a week-long census of all patients in one hospital, asking medical and nursing staff to identify patients under their care who, in their view, either met the offered definition of palliative care ('Palliative care is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with, or dying from, a progressive life-threatening illness, or are bereaved') and/or were terminally ill (defined in advance as having a life expectancy of 3 months or less).¹⁰⁸ Using this approach, the authors found a discrepancy between patients identified as needing SPC according to nursing versus medical staff, and versus their own case note review. A broader formulation of SPC need was used in another survey of hospital health care professionals, in which equity of access, pleasant surroundings, flexibility of visiting hours and discharge planning were included alongside pain and symptom management, psycho-social and spiritual support.¹⁰⁹ These factors were used as an indicator of palliative care needs which were not being addressed by current services, but suggest a lack of understanding of the differences between access and need, and between need and service provision.

Finally, a small number of papers have focused on one aspect of need, including theoretical and empirical formulations of aspects of spiritual SPC

need ^{110;111}, and the needs of families of patients within the palliative care phase of disease. ¹¹²

Routine data, bereaved relative report, patient report and health care professional report are thus all used to approximate need within research studies. A recent review of definitions and approaches to needs assessment in SPC identified three approaches: epidemiological (based on routine population data), corporate (involving engagement with the public) and comparative (a comparison of the provision of care between areas), and argued that a combination of these would be necessary for defining a population's need for care. ¹¹³ The authors argue that the definition of need as 'the ability to benefit from health care' is useful for SPC, and that this may include reassurance, supportive care, and relief of carers as well as clinical benefit. However, they offer no further advice on how this definition may be operationalised and measured.

So, much of the research conducted to date suffers from a lack of clarity of the nature of need for care, and explicit definitions of need for SPC. As SPC claims to benefit patients over multiple domains, not just physical, any definition of need for SPC may be expected to reflect the holistic approach of the service. This is rarely the case.

This review of theory and research to date leads me to suggest the following questions relevant to the current study:

1. How is need for SPC conceptualised and applied within day to day clinical decision-making?
2. Is need for SPC a singular concept, or do multiple versions exist for different purposes or in different contexts?

3. How can need for SPC best be operationalised and measured within research studies?

The question of need for care is essential to investigations of equity, but so is the characteristic by which we are assessing equity – in this case, age. Below, I briefly consider how we may define older age, before assessing the current evidence on how older age is related to the distribution of SPC.

Old age and use of specialist palliative care

Beliefs about when ‘old age’ commences are dependent on our own age. A survey of nearly 2000 people conducted on behalf of Age Concern found that the reported start of old age varied from 55 years amongst 16-24 year olds to just over 70 in those aged 75 and over themselves.¹¹⁴ Within the UK, older age is commonly defined in Government policies such as the NSF for Older People as being the age of 65 or above.⁷ However, this chronological definition of old age is currently under challenge due to medical advances and rising life spans.¹¹⁵ As a result of the ageing population, finer categories of older age have been developed and applied within medical and other research. Thus, we may categorise older persons into the ‘oldest old’ (aged 85 and above), ‘mid-old’ (aged 75 to 85), and ‘young old’ (aged 65 to 75).

Chronological definitions offer only one approach to considering older age. Biological, social and psychological theories of old age offer different perspectives on the defining influences of such categorisations.¹¹⁶ Of particular import for health research, self-perceived age, rather than chronological age, may be a better indicator of health, psychological and social characteristics.¹¹⁷ However, in this study, I focus on chronological age. This is because my assessment of age equity (or inequity) stems from the

requirements of Government policy, which uses age in years rather than other markers of the ageing process.

Four separate reviews have investigated factors influencing access to palliative care, including one specifically on age conducted as background to this thesis.^{15-17;118} These reviews have consistently concluded that the use of SPC services varies according to age. Below, I briefly summarise the currently available evidence on use of SPC in relation to age for patients with cancer.

The majority of studies conducted in this area to date have been retrospective cohort studies using administrative data, ranging in size from 521¹¹⁹ to 170,136 participants [Table 2.1].¹²⁰ Three cross-sectional surveys using retrospective reports of service use from proxy respondents (usually carers) have also been conducted. They included 96,¹²¹ 1271¹²² and 2074^{123;124} participants respectively. Two further studies have been conducted – one used a retrospective case-control design¹²⁵ and one was a retrospective review of a palliative care service' records, with comparisons to the wider population of cancer deaths.¹²⁶ Studies covered deaths occurring from 1979 to 2003. Two studies restricted participants to patients aged 65 years and above at death, and one to 67 years and above; the remaining restricted participants to adults, or had no stated age restrictions.

Table 2.1 Current evidence on use of SPC by age							
Study	Methods	Location	Stated aim	Participants	Outcome	Effect of age on use: univariable analysis	Effect of age on use: multivariable analysis
Retrospective cohort studies							
Burge 2008 ¹²⁷	Retrospective cohort study using administrative data	Canada	To re-examine the relationship between age and palliative care use among cancer patients and identify the multiple indicators contributing to these inequalities.	7511 cancer deaths (1998 to 2003) identified from death certificates in two district health authorities in one province. 18 years and over.	Referral to the municipality palliative care programme. Determined from clinical records of the services.	Over 65 less likely to receive care	Over 65 less likely to receive care, particularly those aged 85 and over
Burge 2002 ¹²⁸	Retrospective cohort study using administrative data	Canada	To determine whether previously determined low palliative care programme referral rates for the elderly have been overcome in recent years.	4376 cancer deaths (1992 to 1997) identified from death certificates in one municipality. No stated age restrictions.	Referral to the municipality palliative care programme. Not stated how determined.	Over 65 less likely to receive care	Over 65 less likely to receive care
Costantini 1993 ¹²⁹	Retrospective cohort study using administrative data	Italy	To identify the characteristics of patients who received palliative home care compared to the general population of patients who died of cancer.	12,343 cancer deaths (1986 to 1990) identified from local department of statistics in one city. 18 years and over.	Use of the palliative home care service. Determined from clinical records of the service.	Over 75 less likely to receive care	-

Table 2.1 Current evidence on use of SPC by age							
Study	Methods	Location	Stated aim	Participants	Outcome	Effect of age on use: univariable analysis	Effect of age on use: multivariable analysis
Evans and McCarthy 1984 ¹²⁶	Retrospective cohort study (with external control group) using administrative data.	UK	To describe the first year's work of a terminal care support team.	125 patients (referred between May 1982 and June 1983) identified from the clinical records of the service and who received continuing care. 437 cancer deaths (1982) in one district identified from the death records of the Office of Population Censuses and Surveys.	Receipt of continuing care from the multidisciplinary terminal care support team.	Over 65 less likely to receive care	-
Gray and Forster 1997 ¹¹⁹	Retrospective cohort study using administrative data	UK	To identify and compare adult residents dying of cancer during 1991 who received SPC and those who did not.	521 cancer deaths (1991) identified from death register held by the Director of Public Health. Participants included if postcode of residence within District Health Authority; cancer recorded as a causal or contributory factor in death. 16 years and over	Receipt of care from one or more SPC agencies, last 12 months of life. Determined from in-patient and day hospice records; Marie Curie and Macmillan nurse' case load diaries	Users mean age at death 66.6 Non-users mean age at death 73.0	-

Table 2.1 Current evidence on use of SPC by age							
Study	Methods	Location	Stated aim	Participants	Outcome	Effect of age on use: univariable analysis	Effect of age on use: multivariable analysis
Hunt and McCaul 1996 ¹³⁰	Retrospective cohort study using administrative data	Australia	To compare the population of hospice cancer patients with non-hospice cancer patients in terms of age, sex, marital status, primary site of malignancy, survival time from diagnosis to death, country of birth and religion of residence.	2800 cancer deaths (1990) identified from Central Cancer Registry (CCR) database. Deaths attributable to a non-cancer cause – based on State death records – excluded. No stated age restrictions.	Use of one of South Australia's inpatient hospice or outreach palliative care services. Determined from lists provided by all hospice and palliative care services of their patients who died in 1990.	Over 80 less likely to receive care	Over 80 less likely to receive care compared to under 40
Hunt 2002 ¹³¹	Retrospective cohort study using administrative data	Australia	To determine the extent of coverage by designated palliative care services of the population of terminally ill cancer patients in South Australia, and to identify the types of patients who receive these services and the types who do not.	3086 cancer deaths (1999) identified from State Cancer Registry database. No stated age restrictions.	Use of one of South Australia's inpatient hospice or outreach palliative care services. Determined from lists provided by all hospice and palliative care services of their patients who died in 1999.	Over 80 less likely to receive care	Over 80 less likely to receive care compared to those under 60
Johnston 1998 ¹⁰²	Retrospective cohort study using administrative data	Canada	To assess the degree to which cancer patients resident in the region who may need palliative care are being referred to the comprehensive palliative care program.	14,494 cancer deaths (1988 to 1994) identified from death certificate data included in the Cancer Registry in one region. 20 years and over.	Referral to a comprehensive Palliative Care Program (PCP) based in one Infirmary. Inpatient unit, hospital consultation, clinic follow-up, home consultation and bereavement support. Determined from clinical records of the service.	Over 75 less likely to receive care	Over 75 less likely to receive care

Table 2.1 Current evidence on use of SPC by age							
Study	Methods	Location	Stated aim	Participants	Outcome	Effect of age on use: univariable analysis	Effect of age on use: multivariable analysis
Keating et. al 2006 ¹³²	Retrospective cohort study using administrative data	US	To evaluate the relative importance of patient characteristics, physician characteristics, individual physicians, and local health centres in explaining variations in hospice enrolment.	3805 lung, colorectal, breast, or prostate cancer deaths (January 1996 to June 2001) identified from one regional integrated health care delivery system	Enrolment in the hospice care programme. Determined from health plan records.	No age difference	Over 75 more likely to receive care
Lackan 2003 ¹³³	Retrospective cohort study using administrative data	USA	To assess the use of hospice by women dying with breast cancer as a function of time period, geographic area, and patient characteristics.	25,161 breast cancer deaths (1991 to 1996) identified from Surveillance, Epidemiology and End Result (SEER) Medicare databases - population-based registry for incident cancer cases. SEER areas represent about 14% of the US population. Diagnosed with breast cancer between 1986 and 1996. Aged 65 years and over.	Receipt of hospice care. Determined by existence of a hospice claim in the hospice standard analytic file [Medicare claims].	Over 75 less likely to receive care	-

Table 2.1 Current evidence on use of SPC by age							
Study	Methods	Location	Stated aim	Participants	Outcome	Effect of age on use: univariable analysis	Effect of age on use: multivariable analysis
Lackan 2004 ¹²⁰	Retrospective cohort study using administrative data	USA	To examine whether use of hospice has changed over time, as a function of sociodemographic characteristics, geographic location, type of insurance and year of death.	170,136 breast, colorectal, lung and prostate cancer deaths (1991 to 1999) identified from Surveillance, Epidemiology and End Result (SEER) Medicare databases - population-based registry for incident cancer cases. Diagnosed with cancer between 1991 and 1996. Aged 67 years and over.	Receipt of hospice care. Determined by existence of a hospice claim in the hospice standard analytic file [Medicare claims].	Over 75 less likely to receive care	-
Sessa 1996 ¹³⁴	Retrospective cohort study using administrative data	Switzerland	To describe the characteristics of a consecutive series of cancer patients seen in the referral centre.	993 cancer deaths (January 1991 to July 1993) identified from clinical data of referral centre for medical oncology (SOC) in one region. Included patients whose treatment had been taken over by the SOC, or for whose treatment the advice of the SOC was regularly being sought. No stated age restrictions.	Use of palliative home-care program in one of five districts - in two districts of the study area this home care includes more nursing and clinical staff and is called 'hospice'. Determined from clinical records of the service.	Over 70 more likely to receive care	-

Table 2.1 Current evidence on use of SPC by age							
Study	Methods	Location	Stated aim	Participants	Outcome	Effect of age on use: univariable analysis	Effect of age on use: multivariable analysis
Virnig 2002 ¹³⁵	Retrospective cohort study using administrative data	USA	To determine disease-specific rates of hospice use before death, and whether hospice use varies across cancer diagnoses or by ethnic group, age or sex.	388,511 deaths from one of seven cancers (1996) identified from the National Center for Health Statistics' Report of Final Mortality Statistics. Aged 65 years and over.	Use of hospice care. Determined from 1996 hospice claims data submitted to the Health Care Financing Administration.	Over 85 less likely to receive care	-
Proxy surveys							
Addington-Hall 1998 ¹²³	Retrospective survey of proxies	UK	To investigate how cancer patients who receive hospice inpatient care differ from those who do not in terms of their socio-demographic characteristics, site of cancer, symptom experience and dependency levels in the last year of life.	2074 of 2094 (71% response rate) cancer deaths randomly sampled from 20 self-selected health authorities. Deaths occurring in last quarter of 1990. For each death, the best informant about the deceased's last 12 months of life sought, and interviewed using a structured questionnaire.	Receipt of hospice inpatient care. Determined by respondent's recollection of the names of hospitals and hospices to which the deceased was admitted. Names cross-checked with the 1990 Directory of Hospice Services.	Over 65 less likely to receive care	Over 75 less likely to receive care

Table 2.1 Current evidence on use of SPC by age							
Study	Methods	Location	Stated aim	Participants	Outcome	Effect of age on use: univariable analysis	Effect of age on use: multivariable analysis
Addington-Hall 2000 ¹²⁴	Retrospective survey of proxies	UK	To explore the factors associated with receiving care from community SPC nurses (CSPC)	2074 of 2094 (71% response rate) cancer deaths randomly sampled from 20 self-selected health authorities. Deaths occurring in last quarter of 1990. For each death, the best informant about the deceased's last 12 months of life sought, and interviewed using a structured questionnaire.	Receipt of CSPC nursing. Determined by respondent's reports of use of these services – no further details.	Over 65 less likely to receive care	Over 85 less likely to receive care
Beccaro et al 2007 ¹²²	Retrospective survey of proxies	Italy	To estimate the distribution of places of care for Italian cancer patients during the last three months of their lives, the proportion receiving palliative care support at home and in hospital, and the factors associated with referral to palliative care	1271 of 2000 (67% response rate) of cancer deaths randomly sampled from country. Deaths occurring between March 2002 and June 2003. Non-professional carer interviewed using structured questionnaire.	Receipt of care from home or hospice palliative care team. Use of palliative care determined from palliative care records.	Over 85 less likely to receive care	No effect of age

Table 2.1 Current evidence on use of SPC by age							
Study	Methods	Location	Stated aim	Participants	Outcome	Effect of age on use: univariable analysis	Effect of age on use: multivariable analysis
McCusker 1985 ¹²¹	Retrospective survey of proxies	USA	To identify factors associated with the use of home care, including home hospice, by patients with terminal cancer	133 cancer deaths randomly selected from deaths in one county, December 1979 to January 1980. Surviving relatives contacted and interviewed (96/133 – 72% response rate).	Use of the county home-hospice programme.	Over 65 less likely to receive care	-
Retrospective case-control study							
Grande 2002 ¹²⁵	Retrospective case-control study	UK	To investigate variables associated with referral to a Hospital at Home (HAH) palliative care service.	121 cancer patients referred to HAH from June 1994 to June 1995 (cases) and 206 cancer deaths randomly sampled from the area Cancer Registry who were not referred to HAH (control).	Referral to the Hospital at Home palliative care service. Not stated how determined.	Users mean age 70.5 Non-users mean age 74.7	-

Four studies focused specifically on the receipt of SPC at home.^{121;124;125;129} The remaining included one or more services providing SPC across a range of settings (e.g. home, hospital, and hospice). Studies based their outcome ascertainment on records kept or provided by the SPC service of interest, except two of the surveys of proxy respondents, which relied on participant's reports of the deceased's use of services.

The majority of the studies reported a statistically significant lower use of SPC among older patients at a univariable level.^{102;119-131;133;135} One study reported a statistically significant higher use of palliative home care among the older age group (70 and over)¹³⁴ and one found no effect of age.¹³²

Ten studies included a multivariable regression analysis to investigate the effect of age on referral to or use of SPC, after controlling for potential confounding factors.^{102;120;122-125;127;128;130-132} Of these, seven reported older adults were significantly less likely to use SPC services.^{102;123;124;128;130;131} However, age group cut-offs and variables included in regression models varied between studies, making direct comparison between them difficult. In Grande et al's (2002) case control study, the effect of age disappeared after controlling for other variables, including use of cancer and district nursing services.¹²⁵ As the authors acknowledged, if age is related to use of other health care services, its relationship with hospice use may have been disguised in their analysis. The effect of age on use of domiciliary palliative care services also disappeared in Becarro et al.'s study of bereaved carers, after controlling for patient and caregiver characteristics including gender, education, marital status, place of residence, primary tumour, and caregiver's relationship, age, gender and education.¹²² Significantly higher use among cancer patients aged 75 and over compared to those younger than 55 was reported in

Keating's retrospective administrative data analysis, which had found no effect of age at a univariable level.¹³²

The majority of studies conducted to date therefore suggest that older cancer patients are less likely to use SPC services. However, this evidence comes from retrospective study designs alone. The widespread use of retrospective approaches in this area is attributable in part to the ease with which researchers can assemble a sample of relevant patients to assess service use within the final few months of life. Additionally, retrospective approaches enable all such patients to be studied, including those who may not prospectively have been identified as approaching death. They thus facilitate the efficient study of the end-of-life experiences of a wide range of patients.¹³⁶ However, a number of important limitations of this approach must be recognised.

Firstly, reliance on routine data and retrospective proxy reports is likely to reduce the accuracy and completeness of outcome ascertainment. Referral to or use of SPC has been shown to be inconsistently recorded in patient medical records;¹⁰⁶ the validity of responses about service use from proxies such as carers is uncertain;¹³⁷ and questions asked of proxy respondents to determine use of SPC are often insufficiently comprehensive.¹²¹ Retrospective studies therefore risk over- or under-estimating use of SPC services. If the recording or recall of service use varies systematically in relation to patient age, bias will be introduced.

Secondly, the availability of data on important predictor factors is limited to that available within medical records, or based on the recall of significant others. Details of symptoms, functional status, and psychological and

spiritual concerns may be lacking or inaccurate.¹³⁸ The ability to ascertain patient need for care is therefore severely limited.

Finally, retrospective study designs of use of services in relation to age and other characteristics have been criticised for risking an over-estimation of differences between older and younger patients.¹³⁹ Systematic bias may be introduced due to the shorter survival time of older patients following the diagnosis of a terminal illness; older patients may therefore appear to have received less treatment during the last months of life. However, these arguments are more applicable to studies considering the intensity of care, rather than the presence or absence of referral to a service.

Aside from the limitations applicable to all retrospective studies, there are a number of quality issues pertinent to the research studies summarised above. Firstly, studies often gave an insufficient description of the location of SPC (home or hospital) and nature of the service.^{120;128;131;133} As SPC services vary widely in their organisation and scope, accurate descriptions of the nature of care are essential in understanding the generalisability of findings. Secondly, the statistical analysis undertaken within studies was often limited. Five studies conducted no multivariable analysis, drawing conclusions about the relationship between age and use of palliative care based on univariable analysis alone.^{119;121;126;134;135} Thirdly, within those studies which did conduct multivariable analysis, critical factors which may be associated with both age and use of SPC, including comorbidity and symptom experience, were not included (with four exceptions^{123;124;127;132}).

Of most concern in the work conducted to date is the lack of assessment of equity, rather than equality, of use. Only one of the studies described above explicitly defined, investigated, or controlled for need for SPC. This, the most

recent study, responded to criticism of earlier work and created proxy variables for need using data available from administrative databases.¹²⁷ The study authors constructed variables for disease burden and severity using type of cancer, comorbidities and length of inpatient stays. However, as they themselves acknowledge, this cannot match approaches which gather data directly from patients.

2.3 Explaining variations in use of palliative care by age

Reduced access to all health care for older patients may arise as a result of rationing, lower need for care, differences in patient preferences or implicit prejudice. These factors are summarised in relation to SPC below.

Explicit rationing of health care by age has been defended on the basis that, as everyone ages, no particular group is being discriminated against in an unacceptable manner (as opposed to, say, rationing by gender or ethnic group).¹⁴⁰ Thus, ageism is argued to be 'value-neutral', and is simply an outcome of different stances on the distribution of care derived by health economists.¹⁴¹ There are three main types of explicit ageism by which care for older people may be denied or limited: 'health maximisation ageism', 'productivity ageism', and 'fair innings ageism'.¹⁴² These concepts may be used to deny access to care, as well as to guide decisions about the amount of a particular health care service that could be offered to older people.

Under the 'health maximisation' approach, decisions about the distribution of health care resources are based on the assignation of a constant value to a year of life, irrespective of age. As younger people are likely to experience health gains for a greater number of years than older people, by default they are likely to be given priority. The key influence here is life expectancy, although this is of course heavily dependent on a patient's age.

The second approach, 'productivity ageism', relates the value of health gains at particular ages with the expected productivity at that age. Productivity may peak during the middle years of life, and fall towards old age, thus leading to limitations on access to care for older adults.

The final approach, 'fair innings', considers health over the course of an entire lifetime, for example by deciding on a certain number of Quality-Adjusted-Life-Years (QALYs) which people may expect to enjoy. Decisions on resource allocation are then made on the basis of achieving the 'fair innings', which may lead to the prioritisation of a young person over an older person.

However, the application of such approaches to decisions about the distribution of SPC may be limited, due to SPC's focus on improving quality rather than length of life. Calculations about the benefits accrued by patients receiving SPC are not easily captured by an approach focusing on life-years gained. Thus, within the rationing debate, SPC has often been seen as an entity separate from other health care services, one that can be offered when access to expensive health technologies has been denied. A leading proponent of age-based rationing, Daniel Callahan, suggested that over a certain age people should receive only palliative and symptom-relieving care.¹⁴³ However, palliative care must still compete against other health care services within any resource-limited health care system. It must also therefore face rationing, and some form of priority-setting. In later work, Callahan argued that, whilst palliative care should be provided at some minimal level to all those in need, the highest priority should be given to palliative care for the elderly, as the older a patient is, and the closer to death, the greater the likelihood that it may be all that medicine can offer them.¹⁴⁴ In a survey of preferences for the receipt of treatment by younger or

older patients, members of the public favoured younger age groups to receive a life-saving procedure, but showed no preference between younger and older groups to receive palliative care.¹⁴⁵

Variation of benefit in relation to age as a reason for the explicit rationing of care is upheld by NICE. A recent consultation document published by NICE on the use of social value judgments in allocation decisions suggested that 'where age is an indicator of benefit or risk, age discrimination is appropriate'.¹⁴⁶ A reduced ability to benefit from SPC may therefore be one explanation for reduced access to care. Evidence of benefit in relation to age is, however, often limited, due to the widespread exclusion of older people from clinical trials.^{147;148} This is particularly problematic in SPC, where there is a paucity of evidence of effectiveness.¹⁴⁹ What evidence there is, based upon the presence and impact of symptoms, is limited and conflicting.

One post-bereavement survey of carers found that patients of all diagnoses over 85 years had a greater number of symptoms than patient under 65, but symptoms in the older group were less likely to 'very distressing'.¹⁵⁰ By contrast, a secondary analysis of a retrospective survey of carers of cancer patient suggested that both the number of symptoms and the proportion perceived to be 'very distressing' declined with age, whilst the level of functional dependency did not vary.¹⁵¹ The finding that older palliative care patients may have fewer interventions for symptom control, suggesting a lower need for care,¹⁰¹ has been related to a tendency for older patients to under-report pain.¹⁵²

It has been argued that the need for SPC should be determined by social, emotional and spiritual concerns as well as by health status.¹⁵³ Across a life span, patients' health, social and economic status (including the presence of

dependent children or partners, the likelihood of living alone and employment status) fluctuates. It is therefore possible that the need for SPC will vary with age. Older cancer patients may have fewer and less severe psycho-social problems than younger patients, and experience less disruption and carer burden.¹⁵⁴ If need for SPC is assessed on this basis, older patients may have a lower use of these services.

A further reason for a reduced use of SPC in relation to age is that the needs of older adults may be more likely to be met by other services. General practitioners, district nurses and hospital doctors and nurses are all providers of generalist, rather than specialist, palliative care. It is possible that older cancer patients are sufficiently cared for by these professionals. However, evidence to support this argument is lacking. Policies state that all those with complex needs should have access to SPC, and it remains uncertain whether older patients are more or less likely to have 'complex needs', howsoever defined.¹⁹ One small UK study has shown that patients not referred to a palliative hospital at home scheme were also less likely to be receiving other forms of care such as district nursing, suggesting age may be a barrier to all types of care at the end of life.¹²⁵

Differences in patient attitude and choice may lead to differential use of services. However, one UK survey of adults aged 55 and over found no differences between older and younger groups on attitudes to hospice and palliative care, or the belief that younger patients should take priority.¹⁵⁵

Finally, variations in the use of SPC may arise because of prejudicial attitudes amongst those who refer patients to or accept patients into SPC. Stereotyping and stigmatisation of the elderly was first referred to as ageism in the 1960s by Robert Butler, a US geriatrician who attributed such

behaviour to younger peoples' revulsion and fear towards growing old, disease, disability and death.¹⁵⁶ Ageism relates to stereotyping of and prejudice against older people, arising from the belief that people are less productive, attractive and intelligent as they age.¹⁵⁷ Age discrimination may occur as a result of ageist attitudes, and describes behaviour in which older people are treated unequally.¹¹⁴ However, such behaviour is not necessarily always negative. Compassionate ageism may lead to older patients being offered more care due to perceptions they are needier. This contrasts with conflictual ageism in which elderly people are perceived to be burdensome or less deserving, and are thus avoided or sidelined.¹⁵⁸ Callahan's views on prioritising SPC access for the elderly demonstrate the former approach. Evidence that older people are less likely to be offered SPC suggests the latter, more negative view.

Ageism may not be confined to the attitudes of (normally younger) health care professionals towards older patients. Older adults may themselves hold negative views about their own age group, known as 'self-stereotyping'. This has been attributed to the internalisation of a lifetime's exposure to cultural attitudes (usually negative) towards the elderly.¹⁵⁹ Such attitudes may lead to the attribution of symptoms of illness to ageing rather than disease, and reduce the likelihood of seeking or accepting medical care.¹⁶⁰

The effect of negative attitudes on clinical decision-making is difficult to ascertain. As Dey and Fraser state:

*Precisely because clinical judgement is meant to involve a holistic assessment of individual needs, it is no easy matter to assess the way age is used at the clinical level. If clinical decisions involve age-based rationing, they are likely to be covert.*¹⁶¹

Research suggests that the influence of ageist attitudes on such decisions may not even be recognised by the decision-maker themselves. 'Implicit ageism' is defined as thoughts, beliefs and feelings about the elderly 'that exist or operate without conscious awareness, intention or control'.¹⁶² Measures of ageist attitudes tend to find a lower proportion of negative views on explicit compared to implicit measures.¹⁶² Individuals may not even be aware that stereotyping of older people is influencing their behaviour, and may attribute decisions to withhold or restrict treatment to alternative explanations which sit more comfortably with their self-conception as a non-ageist individual.¹⁶³

Perhaps due to difficulties in researching this area, suggestions of ageism within palliative and cancer care are based predominantly on extrapolations from evidence of treatment disparities, rather than measures of perception.^{11:164} However, one UK survey of the attitudes of oncology professionals (medical, nursing and radiography staff) towards older patients has found consistently negative views were held.¹⁶⁵ This suggests the possibility that such attitudes may be present within SPC too.

Summary

This review of social justice, equity and need has shown how access to health care is shaped by societal and individual preferences about the distribution of goods to individuals. Whilst Government policy is strongly supportive of equal use of SPC, regardless of patient age, there is a suggestion that prejudicial attitudes and discrimination may remain. Additionally, the Government commitment to prioritising care for particular patient groups to reduce inequalities adds a further dimension to observations of the process by which care is distributed at all levels. SPC is a particularly interesting topic of investigation into the fair use of care, as its holistic nature challenges

the methods frequently used to define and measure need for care. It is also, therefore, particularly important that the context in which decisions are taken, and the influences on such decisions, are acknowledged and explored to comprehensively investigate whether care is provided equitably.

In this thesis I base my ethnography of SPC provision within the dominant theory of need within public health, the capacity to benefit from health care, exploring its relevance to the definition, operationalisation and measurement of need for SPC. I consider how my survey findings relate to accounts of equal access to health care, both 'equal opportunity' and 'capability' views, and the relevance of each to the field of SPC.

In the next chapter, I turn to the particular methodological underpinnings of the thesis. I explore how mixed methods research originated and developed, and the major controversies in the integration of qualitative and quantitative methods. I then explain how I applied these methods to the design and conduct of this research study, and provide full details of the planned phases of work.

Chapter 3

Methodological overview

*And if the world were black or white entirely
And all the charts were plain
Instead of a mad weir of tigerish waters,
A prism of delight and pain,
We might be surer where we wished to go
Or again we might be merely
Bored but in the brute reality there is no
Road that is right entirely.*

Louis MacNeice, 'Entirely' ¹⁶⁶

This project set out to investigate variations in the use of SPC, and in particular whether older age leads to a reduction in use of these services. The central question, therefore, is whether the use of SPC is equitable in relation to age. Within the NHS, need for care should determine use. Therefore, to unpick this question, I also wished to examine how need for SPC is conceptualised, and which factors might cause this conceptualisation to change in the minds of providers. Additionally, once I had an idea of what constituted need for SPC, I wished to consider how I could measure such need to assess use.

The most appropriate methods for answering these questions are mixed. Qualitative techniques are particularly suited to exploring conceptualisations of need. Yet quantitative techniques are the appropriate approaches for measuring use in relation to need. The combination of both approaches enables the full range of questions to be explored and answered.

Additionally, it enables findings from one phase of work to influence other

phases, generating a holistic and comprehensive investigation into the area of concern.

To trace the development and conduct of this research, within this chapter I present in detail the methodological approach taken, and its relationship with the research question. It opens with an overview of the field of mixed methods research. I then explore the history of mixed methods and key current questions in its application, with particular reference to the philosophical underpinnings of this approach. Drawing upon the theoretical justifications for the methods chosen, I then demonstrate how I developed the study design. Finally, the linkages between qualitative and quantitative methods in this study are explored.

3.1 The nature of mixed methods research

The combination of quantitative and qualitative data within one study is not a new phenomenon.¹⁶⁷ However, it is only in the last twenty years or so that 'mixed methods' has gained momentum and prominence as a distinct movement within social science research. As a new and developing approach, considerations of philosophy, theory, values, methodology and methods are still being debated. Whilst it is essential for all researchers to pay attention to the clarification of and justification for their approach, in the still emerging discipline of mixed methods research this is particularly important. To provide a clear foundation for my work, within this and the following sections I review current thinking, and state my particular stance, across six key issues in mixed methods research:¹⁶⁸

1. Definitions
2. Utility
3. Philosophical basis

4. Design considerations

5. Inference

6. Logistics

What is mixed methods research?

Mixed methods research has been defined as:

...the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration. ¹⁶⁷

Therefore, the inclusion of both quantitative and qualitative approaches within a study is the traditional basis for mixed methods.

Why undertake mixed methods research?

Greene, Caracelli and Graham devised an influential scheme summarising different (although potentially overlapping) purposes for mixed methods research: ¹⁶⁹

- Triangulation: looking for convergence or corroboration by using different methods
- Complementarity: using results from one method to elaborate or clarify results from another method
- Development: using results from one method to develop or inform the other method
- Initiation: using different methods to look for contradictions or new perspectives on results or questions
- Expansion: using different methods for different components of a study to extend the range of inquiry

Justifications for why methods should be combined may vary depending on authors' aims, beliefs and values. A number of protagonists who argue that mixed methods are the 'best' way to conduct research claim that it can answer research questions not amenable to quantitative or qualitative approaches alone; that it can provide stronger ('better') inferences; and that it enables the presentation of a greater diversity of views.¹⁷⁰ Other authors who do not subscribe to the thesis that mixed methods are the only way forward have argued that the incorporation of more than one method simply enables a broader understanding to be developed, if required.¹⁷¹

In practice, the reasons for using mixed methods are more diverse, and sometimes less obvious, than conceptualisations suggest. Following a review of published mixed methods studies, Bryman identified 18 possible reasons for methods to be combined, with complementarity (as defined by Greene et. al.¹⁶⁹) being the most common.¹⁷² However, stated rationales for mixing methods did not always correspond with subsequent practice, and Bryman warns researchers to be aware that the outcomes (and thus the rationale behind) mixed methods studies may not always be predictable as studies progress.

Whilst consideration of the purpose of mixed methods research helps clarify its aims, the rigid schemes put forward (as Bryman demonstrated) are not straightforwardly applied to practice. In particular, multiple reasons for mixing methods may be viable within one study, as methods and results interact with each other. The importance is in clarifying that mixed methods are the appropriate approach to answering the research question at hand, and to clearly state how, and why, the methods and results are to be combined.

3.2 Philosophical considerations in mixed methods research

As an emerging approach, mixed methods researchers are engaged in ongoing debate amongst themselves and with researchers from other approaches as to the appropriate philosophical underpinning for mixed methods research. This debate is heavily tied to claims for the legitimacy of mixed methods, which depend on arguing that quantitative and qualitative approaches and methods can be logically combined. Such claims have been fiercely resisted on philosophical grounds. In practice, the debate on combining quantitative and qualitative approaches operates at two levels: the philosophical, and the technical (method).¹⁷³ In this section I clarify the origins of this debate, its current status, and how this relates to research practice.

Key definitions

Firstly, though, a note on definitions is required. Terminology used in the debate about quantitative, qualitative and mixed methods approaches is often employed with different intentions and meanings. A key term in these debates is 'paradigm'. Originating in Kuhn's work on revolutions in scientific knowledge, there are multiple concepts of paradigms. One summary of the different definitions in use is outlined by Morgan, who argues they may be nested within each other, as adapted in Figure 3.1.¹⁷⁴

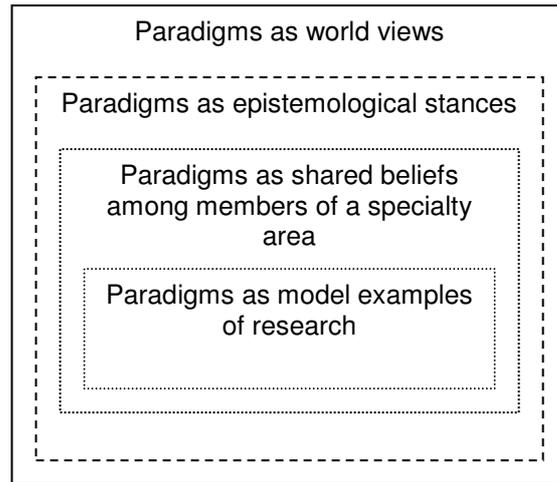


Figure 3.1 Morgan's definitions of paradigms

The broadest definition of paradigms is as world views, covering our thoughts and beliefs about, potentially, everything. The next definition in use associates paradigms with belief systems, and thus has a narrower focus on epistemology or philosophy of knowledge (one part of a world view). In this conceptualisation, stances such as positivism and constructivism are paradigms. This is a commonly used concept of paradigms, and one on which the incompatibility debate (the impossibility of combining quantitative and qualitative approaches, discussed in more detail below), is based. Morgan's third paradigm definition is that of the set of beliefs shared by particular communities of researchers; which research questions should be asked, and how can they best be answered? Finally, a little-used idea of paradigms, although one that Kuhn himself was particularly interested in, is one that sees paradigms as 'exemplars' for best research practice.

Discussion of paradigms inevitably relies on ideas about ontology, epistemology and methodology. Ontology can be defined as concerning the nature of reality. Epistemology concerns the nature of knowledge; methodology concerns how to generate this knowledge.¹⁷⁴ Whilst

methodology is commonly accepted as being about more than just methods, the two are sometimes conflated ¹⁷⁵. Conversely, ideas of methodology are also on occasion pushed as far as being synonymous with epistemology. ¹⁷⁶ Method is defined as the actual techniques of doing; the practical data collection and analysis.

Quantitative, qualitative and the rise of mixed methods approaches

A number of key phases in the history of methodological approaches in social and behavioural sciences have been posited, stretching back well over one hundred years. ¹⁷⁷ A brief review of these is useful to understand where mixed methods approaches, and their philosophical underpinnings, came from. If we take the idea of paradigms as epistemological stances, the initial, dominant paradigm was that of positivism, with its tenets of objectivism and use of quantitative, hypothesis-driven methods. From the start of the 20th century, purist (logical) positivism was at first challenged, and then overturned, by an emerging qualitative research paradigm drawing on constructivist/interpretivist stances of subjectivism and inductivity. In response to these new ideas, positivism morphed into post-positivism, with its acceptance that true objectivity is an impossible ideal. Alongside this, however, also came new emerging qualitative philosophies such as post-structuralism. Adherents of the new qualitative and quantitative approaches became enmeshed in a sometimes strident debate (often referred to as the 'paradigm wars') about the incompatibility between the two, discussed in detail below. With its early roots in the late 1960s, this debate gave rise to the pragmatist paradigm, alongside the explicit use of mixed methods.

By using this version of methodological history, quantitative and qualitative approaches are characterized as two distinct entities. This is problematic, as the binary conception of 'quantitative/qualitative' is a false dichotomy.

Qualitative inquiry is not one tradition, but many; the categorisation of non-positivist research as 'qualitative' was a way of enabling diverse researchers to claim their place in the mainstream under one banner.¹⁷⁵ Additionally, the distinctions between 'quantitative' and 'qualitative' are often overstated. Instead, it has been argued that research approaches lie on a continuum, with only a few 'purists' marking either end of the spectrum [Figure 3.2].¹⁷⁸

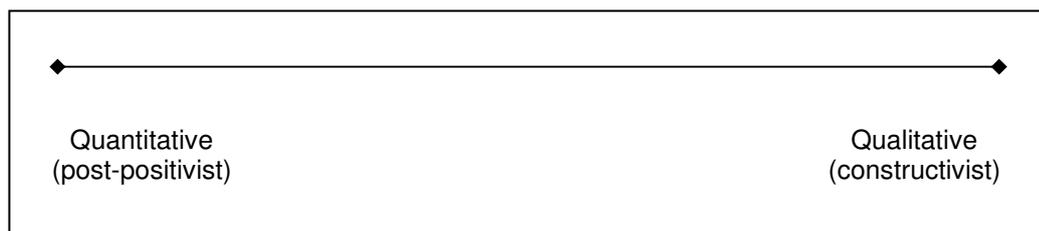


Figure 3.2 The epistemological continuum

However, I follow the stance of Johnson et. al. in distinguishing quantitative and qualitative approaches for the purposes of this discussion, broadly aligned to post positivism and constructivism respectively, whilst acknowledging that the 'real life' position is not as clear as this usage would suggest.¹⁶⁷

Adopting the concept of 'quantitative' and 'qualitative' approaches, then, how might these be defined, and what are the key differences between them? Reichardt and Cook provided a useful summary of the attributes of traditional 'quantitative' and 'qualitative' approaches, as adapted in Table 3.1.¹⁷⁹

Table 3.1 Qualitative and quantitative approaches	
Qualitative inquiry	Quantitative inquiry
Advocates the use of qualitative methods	Advocates the use of quantitative methods
Interpretivism/constructivism	Positivism/post-positivism
Naturalistic and uncontrolled observation	Obtrusive and controlled measurement
Subjective	Objective
Close to the data: the “insider” perspective	Removed from the data: the “outsider” perspective
Grounded, discovery-oriented, exploratory, expansionist, descriptive and inductive	Ungrounded, verification-oriented, confirmatory, reductionist, inferential, and hypothetico-deductive
Process-oriented	Outcome-oriented
Valid; “real”, “rich” and “deep” data	Reliable; “hard”, and replicable data
Ungeneralisable: single case studies	Generalisable: multiple case studies
Holistic	Particularistic
Assumes a dynamic reality	Assumes a stable reality

Four major differences between quantitative and qualitative approaches can be outlined, based on:

1. Their differing epistemologies (positivist versus constructivist)
2. The perceived purpose of their research (explaining facts and causes versus understanding social phenomena)
3. Their approach to research (experimental versus observational), and
4. The role of the researcher (detached versus immersed).¹⁸⁰

Within the quantitative approach, a move away from positivism’s rigid belief in objectivism (that reality exists and is measurable) led to post-positivism, a more moderate version which none the less still adheres to central tenets of cause and effect, reductionism (the selecting and testing of particular variables), empirical observation, and theory verification.^{181;182}

Constructivism (often used as an over-arching term to encompass interpretivism, naturalism and phenomenological approaches) contends that reality is socially constructed, and thus multiple, subjective and liable to

change. The emphasis is on developing understanding and exploring relationships and values inherent in the research process.¹⁸³

The presence or absence of a link between quantitative and qualitative epistemologies and particular methods is fervently debated, and will be discussed more below. The quantitative paradigm is typically associated with methods involving ‘numbers and statistics’ such as cross-sectional surveys with closed questions, and the qualitative paradigm with ‘words and narratives’ such as in-depth interviews and focus groups.¹⁸¹ The association of these epistemologies with particular methods formed the basis for the so-called ‘paradigm wars’ which occurred within the social sciences, particularly educational research, and which subsequently influenced the development of mixed methods approaches.

The ‘paradigm wars’ and the emergence of mixed methods

The basic tenet of the debate which has been referred to as the ‘paradigm wars’ is whether quantitative and qualitative approaches are incommensurate or not. The ‘incompatibility thesis’ states that the quantitative and qualitative research paradigms are and should remain totally separate.¹⁸³ Advocates of this approach argue that the ontological, epistemological and methodological gulf between quantitative and qualitative research precludes any combination of these approaches.¹⁸⁴ As Guba’s oft-quoted phrase summarises:

*the one [paradigm] precludes the other just as surely as belief in a round world precludes belief in a flat one.*¹⁸⁵

Thus, in its early stages, the paradigm debate was characterised by a clear quantitative versus qualitative divide.^{186;187} However, with the rise of the

'compatibility thesis', the argument was made that the deliberate combination of quantitative and qualitative approaches was not only possible, but should be encouraged.¹⁸³ Consequently the idea of a 'third paradigm', that of mixed methods research, was raised.²⁹ As mentioned above, the debate actually took place on two levels or over two issues; whether different quantitative and qualitative methods can be combined, and/or whether different epistemologies or philosophies prevent or enable the combination of quantitative and qualitative approaches.

Teddlie and Tashakkori provide one view of the debate as it currently stands, defining six different schools of thought on quantitative, qualitative, and mixed methods research.¹⁸⁸ A consideration of these different approaches emphasizes that the debate on the combination of methods is by no means resolved. It has continued to be confused by differing concepts of paradigms; as worldviews, as epistemologies, or as shared sets of beliefs among researchers. Clarity over whether the combination is of methods alone, or of something greater than methods (requiring the use of different philosophical approaches, or a new philosophical approach, for example), is required both at the level of methodological debate, and when developing and designing a mixed methods study. The different schools are summarized below:

1. The 'a-paradigmatic' stance.

This stance argues that methods and epistemology are not linked in 'real world' research. Research should continue independently from the paradigm debates, with methods employed without reference to wider metaphysical considerations. One study found that this often was the case, with mixed methods academics usually not considering ontology or epistemology at all in their work.¹⁸⁹ The author's assertion that such academics were taking a

'pragmatic' approach is, however, a potential source of confusion within the mixed methods debate – there can be a difference between a philosophical stance based on pragmatism and a 'doing what works' attitude, discussed in more detail below. Finally, the 'a-paradigmatic' stance is not found in the work of the leading exponents of mixed methods research, who argue strongly for a philosophical basis to all work to foster high quality research underpinned by deep methodological understanding.^{29;170}

2. The incompatibility thesis.

As already discussed, this stance states that quantitative and qualitative approaches are fundamentally incompatible due to their different epistemologies, which are strongly linked to particular methods; they (and their methods) may not, therefore, be mixed. Teddlie and Tashakkori argue that this concept is now discredited, but in fact it can still be found.^{184;190}

3. The complementary strengths thesis

Adherents of this view believe that it is possible to mix methods, but researchers who do so must retain the assumptions of each paradigm. Under this stance, either qualitative or quantitative methods will be the driving force behind a study, and dictate the epistemological stance used. Other methods may be used to triangulate results only, and must be kept separate from the other strands of work until then.¹⁷¹

4. The single paradigm thesis

Following on from the links made between quantitative methods and post-positivism and qualitative methods and constructivism, many protagonists have suggested a single paradigm to support the mixed methods approach. Pragmatism has been suggested as the philosophical basis for mixed methods by a number of commentators.^{170;174;176;183}; due to its prominence in

the debate, this will be discussed in more detail below. The transformative-emancipatory approach has also been suggested as the underpinning for mixed methods approaches, although its focus on disadvantaged groups and power dynamics may limit its appeal.¹⁹¹

5. *The dialectic stance*

The dialectic stance, as advocated by Greene and Caracelli, embraces multiple stances and paradigms within one study, emphasising the importance of juxtaposing viewpoints and exploring the tensions that arise from this within mixed methods research.¹⁹² As they themselves admit, the practice of such an approach within a mixed methods design can be challenging, due to the complexities of incorporating different philosophical perspectives within the same project.

6. *The multiple paradigm stance*

Creswell, amongst others, has argued for the use of multiple paradigms, dependent on the mixed methods design being employed, but with only one paradigm within a particular study.¹⁹³ Such an approach means that post-positivism might be the approach taken within one study with a quantitative focus, whilst interpretivism might be favoured in, for example, a predominantly qualitative study. This approach thus links differing paradigms with particular research designs rather than methods, a variation on the traditional epistemology/methods partnership. It differs from the complementary thesis approach in allowing mixing to take place at any stage of the design and conduct of a study, rather than being confined to the triangulation of results from one dominant approach. It places pragmatism as just one of a number of possible approaches which may be taken within a 'toolkit' of epistemologies.¹⁹³

Another strand of the debate on the compatibility, or otherwise, of quantitative and qualitative approaches is the efforts made, mainly by mixed methods researchers, to find similarities between the two traditions. For example, Johnson and Onwuegbuzie argue that both approaches use empirical observations, make efforts to maximise validity or trustworthiness, and attempt to make assertions about people and their environments.¹⁹⁴ This, they assert, means the approaches are not as different from each other as might be suggested.

Amongst the debate outlined above, an alternative foundation for mixed methods research has been proposed, the philosophy of pragmatism. Pragmatism's role in shaping current debate on the combination of quantitative and qualitative methods is considered below.

The pragmatic approach and mixed methods research

Classical pragmatism originated with late nineteenth/early twentieth century early philosophers such as Charles Sanders Peirce, William James, John Dewey, George Herbert Mead, and Arthur F Bentley.¹⁷⁶ Whilst there are many versions of pragmatism, and thus no one definition which can be offered, one common central tenet (the 'pragmatic maxim' of Peirce) is that the meaning of ideas should be clarified by considering their practical consequences.¹⁹⁵ Thus, pragmatic research is guided by its anticipated consequences; where we want to end up will govern what questions we are interested in researching, and how we wish to do this. Pragmatists view research as taking place in particular contexts (social, historical and political), and thus what is 'right' now may not be 'right' at another time.¹⁷⁴ Pragmatism embraces the concept of the existence of 'the real world', but it does not believe you would ever know if you had got at 'reality' or not; that

is, it rejects foundationalism.¹⁹⁵ Finally, pragmatism acknowledges the role of beliefs and values in decisions made by researchers.²⁹

One particular criticism of pragmatism and its focus on providing validation for beliefs is that our beliefs may all be consistent yet incorrect, or that there may indeed be bodies of beliefs that differ between themselves, but which are all internally consistent. In defending the pragmatic approach within qualitative research from this charge, Avis argues that to develop understanding of a situation or problem there must exist some shared beliefs between the researcher and the researched.¹⁹⁶ As researchers do apparently successfully manage to interpret other's behaviours and norms, he asserts that, from a pragmatic point of view, it seems unlikely that our systems of beliefs are incommensurable or entirely false.

Pragmatism formed the underpinning for Howe's influential 'compatibility approach', supporting the thesis that quantitative and qualitative stances were compatible at both the method and epistemological level.¹⁸³ Teddlie and Tashakkori subsequently made six points about the utility of a link between pragmatism and mixed methods research:¹⁸⁸

1. Pragmatism rejects the incompatibility thesis, and supports both quantitative and qualitative approaches in the same study.
2. The research question is of primary importance, subsuming the methods chosen or the paradigm that might underlie that method.
3. Pragmatism also rejects the 'forced choice' between post positivism and constructivism, instead embracing both points of view.

4. Decisions about the use of methods (mixed, quantitative or qualitative) are dependent on the current research question and the developing research project.
5. Pragmatism rejects the emphasis on metaphysical concepts ('truth', 'reality') that have previously driven much of the debate.
6. Pragmatism is practical and applied.

As pragmatism has developed with the work of authors such as Rorty ¹⁹⁷ and Cherryholmes, ^{195;198} new strands are emerging. ¹⁷⁶ In particular, three aspects (or levels of application) of neo-pragmatism can be defined.

1. Epistemological pragmatism locates pragmatism as a theory of knowledge, arguing that inquiry (the development of knowledge) cannot be guided by any particular set of rules, but instead by the impact of experience on thinking and the consideration of consequences of thought.
2. Meta-methodological pragmatism uses pragmatic principles to examine concepts within research methodology. Maxcy locates Howe's use of pragmatism in his compatibility thesis, and the subsequent justification of mixed methods, within this tradition. ¹⁷⁶ The neo-pragmatism of Richard Rorty, with its rejection of any attempt to find a set of rules or develop one 'reliable method', is also seen as part of this level of pragmatic thought. ¹⁹⁹
3. Methodological pragmatism takes two forms. In the first, pragmatism itself can be a method for choosing research methods. In this, the best method is one that is found to be most effective ('what works'); that is, pragmatic concepts guide choice. ¹⁸⁸ This approach is consistently

encountered within mixed methods. In the second form of methodological pragmatism, pragmatism becomes a broad method of inquiry in itself. Accepting that research, and researcher, are located within particular contexts, pragmatic approaches are used to explore the most valuable methods, and the meaning these have within that context.

The link between pragmatism and mixed methods research has been criticised by some qualitative researchers, who argue that pragmatism is a position available within any paradigm (e.g. post-positivism, constructivism), and as used by mixed methodologists is in fact post-positivist in nature.¹⁸¹ In part, this is a reaction against the perceived 'loss of ground' by qualitative researchers who feel quantitative researchers have embraced qualitative methods to subsume them within their approach to research.¹⁷⁵ In partial agreement with this, Maxcy has acknowledged that methodological pragmatism, in its first form, comes close to post-positivist perspectives, with the potential for reliance on empirical notions of effectiveness.¹⁷⁶

An alternative position to this debate is offered by sociologist David Morgan. He rejects the use of 'paradigm' as a useful term, and instead proposes a pragmatic approach to methodology defined by three major themes:¹⁷⁴

1. An abductive approach to connecting theory and data
2. An intersubjective relationship with the research process
3. An emphasis on transferability in making inferences from data

This contrasts with the inductive-subjective-contextual approach of qualitative research and the deductive-objective-generalising approach of

quantitative research, both of which he acknowledges continue to be useful. Morgan argues that abductive reasoning (moving back and forth between theory and actions to examine those theories) is familiar to anyone who combines quantitative and qualitative methods sequentially. Subjectivity and objectivity he views as unrealistic ideals; intersubjectivity incorporates different frames of reference without conflict. Finally, Morgan rejects the dichotomy between all knowledge being context-specific, or being universal, setting out instead the importance of reflecting on the utility of results in other contexts.

Pragmatism and/or mixed methods (the terminology varies, although the proposed link between the two does not) have been argued to form a 'third paradigm' by a large proportion of mixed methods researchers.¹⁸⁸ This has been aggressively promoted as the 'best' way to do research by those who wish to see the end of 'purist' quantitative and qualitative research as separate approaches.¹⁷⁷ However, there is still a lack of clarity about how pragmatism shapes mixed methods. If pragmatism is to form a true and useful basis for mixed methods, we perhaps need to move away from previous paradigmatic debates. Morgan offers a moderate and, in my view, useful approach here by attempting to reorient the issue outside of confining terminology, thus providing a fresh look at how we can approach different research questions. This draws on pragmatism as both a philosophical and a practical approach, offering a holistic framework within which to conduct research, whether using quantitative, qualitative or, of course, both methods. I have therefore drawn upon Morgan's approach in the design and conduct of this study, using in particular the concept of abductive reasoning to consider the links between theory and data.

Having considered the philosophical framework of mixed methods approaches, and identified pragmatism as a useful basis for this, I turn to briefly consider suggested mixed methods designs and issues of inference and quality.

3.3 The design and conduct of mixed methods research

A key consideration in the design of mixed methods studies is the nature of the combination which takes place. Is the mixing in the methods alone; or does it take place in the formulation of the research questions, methods, analysis and inferences made? ²⁰⁰ There is an increasing consensus that mixed methods designs must aim to fully integrate quantitative and qualitative findings to make useful inferences. ¹⁶⁷ Studies which use both methods within a program of work, but keep the designs, results and discussions from quantitative and qualitative strands entirely separate, are not therefore seen as integrated mixed methods approaches. Labels such as 'partially mixed' versus 'fully mixed' are suggested to distinguish potentially 'insufficiently' mixed studies. ²⁰¹ However, the debate over how quantitative and qualitative methods and analysis may actually be combined continues.

Within this debate, a particular emphasis has been placed on the development of mixed method design typologies to guide researchers. In 2007, Creswell identified twelve different typologies of mixed methods. ²⁰² As Morse noted, this plethora of typologies reflects in part a search for the definitive design taxonomy for mixed methods. ²⁰³ A review of suggested typologies reveals four major dimensions of interest: ¹⁷²

1. The timing of quantitative/qualitative aspects of a study (whether concurrent or sequential)

2. The emphasis placed on quantitative and qualitative methods (quantitative dominant, qualitative dominant or equal status).
3. The reason for the integration (e.g. complementarity, triangulation)
4. The stage at which mixing occurs (e.g. during data collection, data analysis, data interpretation).

However, most of these typologies have been developed theoretically, and they do not necessarily relate to the actual conduct of mixed methods research.¹⁷² Cresswell, for example, argues that his suggested designs (such as the sequential exploratory design or concurrent triangulation design) should not be combined, but there is no practical justification for such an assertion, and studies may require a complex web of interactions between data, analysis and inference to answer the research question. So, whilst typologies (or the common dimensions of typologies) are useful as guiding considerations in the design of a mixed methods study, I believe that the appropriate design should be dictated by the research problem which is to be addressed.

Inference in mixed methods research

An additional important aspect of mixed methods studies is the inferences which are made as a result of conducting such research. A distinction may be made between the results of a study, and the inferences that are made from these findings.¹⁸⁸ Results are the product of data collection and analysis; inferences are the interpretation of these results by the researcher, whether derived inductively or deductively (or, as Morgan would argue, abductively). To move away from terminology used exclusively within quantitative or qualitative approaches, Teddlie and Tashakkori suggest the use of the term inference quality to refer to the internal validity (a quantitative term) and/or credibility (a qualitative term) of a study.¹⁸⁸

Inference quality can be further divided into design quality (referring to standards for methodological rigour) and interpretive rigour (referring to standards for the accuracy of the conclusions). Whilst this terminology is still debated, the underlying principles offer a useful framework for designing and concluding a study firmly founded in a mixed methods approach.

Of course, quality judgements about methodology and the derivation of conclusions within a mixed methods study draw upon the same key issues as those in a qualitative or quantitative study. Questions such as the relevance of the design to the research question, the appropriateness and application of the data analysis techniques used, and the consistency of inferences with current knowledge and theory can be applied to any methodological approach. The issue here is not that mixed methods require a different approach to assessing quality and rigour, but that to create clarity within studies drawing upon multiple research traditions, different terminology may be required.

A major issue for mixed methods studies is how inferences based on qualitative and quantitative approaches may be combined or contrasted to develop a holistic view of the issue under investigation. As a result of this challenge, 'rules of integration' for quantitative and qualitative results have been suggested by Erzberger and Kelle.²⁰⁴ They argue that the combination of quantitative and qualitative results to examine a specific research question may lead to three situations:

1. Convergence
2. Complementariness, or
3. Divergence or contradiction

In the first instance, the convergence of quantitative and qualitative results may lead to the same inferences being drawn, based on both data sets. In the second, quantitative and qualitative findings may relate to different aspects of a phenomenon, but be complementary, enabling them to be used to supplement each other. In the final situation, qualitative and quantitative results may be completely divergent, or contradict each other.

These situations require different approaches to the integration of data, based above all on hypothesised linkages between theoretical considerations on the phenomenon of study, and the empirical data at hand.²⁰⁵ In aiming to integrate results, therefore, expectations of convergence or complementariness should be clarified in advance of the study. In a situation where findings diverge from or contradict each other, consideration must be given to whether this is as a result of a lack of rigour in study conduct, or a mistake in the original theoretical and empirical assumptions, which may then need to be cautiously revised and re-tested. Pragmatic considerations, as advanced by Peirce, form a central aspect of these approaches, applying logical reasoning in the light of theory and previous experience to the empirical data.

The logistics of mixed methods research

Finally, then, following this overview of the origination, philosophical underpinnings and current debates in mixed methods research, what are the implications for the actual 'doing' of such studies? There are as yet few published mixed methods studies which use pragmatism as a specifically defined approach, in spite of its dominance in the methodological literature. In health services research, studies drawing on dual approaches of post-positivism and constructivism have encountered problems with drawing upon both stances, or with conflicting results.^{206;207} This suggests that the use

of a pragmatic framework to guide the choice of research question and study design may be helpful, albeit challenging.¹⁸¹ As Bryman has noted, mixed methods studies in practice otherwise risk being separate quantitative and qualitative studies with no integration.¹⁸⁹

The next sections apply these considerations to set out the approach and overall study design I used in this project.

3.4 Mixed methods and the design of this study

A vital consideration in pragmatic mixed methods research is the relationship between the research question/s and chosen study design. Once the area of research has been refined, this will drive the choice of methods to obtain the best 'fit' between question and design. The emphasis within pragmatism is therefore on using whichever methods will generate suitable data for the research question, rather than asking questions which only fit particular epistemological viewpoints, methodologies and methods.

As the introduction to this thesis highlighted, the goal of this piece of work was to provide high-quality data on use of SPC services, in relation to need. To accomplish this, it was also necessary to undertake a comprehensive assessment of how need for SPC is operationalised by those who provide such care. This section briefly reiterates the aims of the study before explaining the overall study design developed to meet these aims.

Overview of study aims and objectives

The aim of this work was to examine providers' conceptualisations of need for SPC, and the extent to which use of SPC services in lung cancer patients varies according to age. To clarify the areas of investigation, the pathway to

use of SPC was visualised and potential areas of investigation mapped onto it [Figure 3.3].

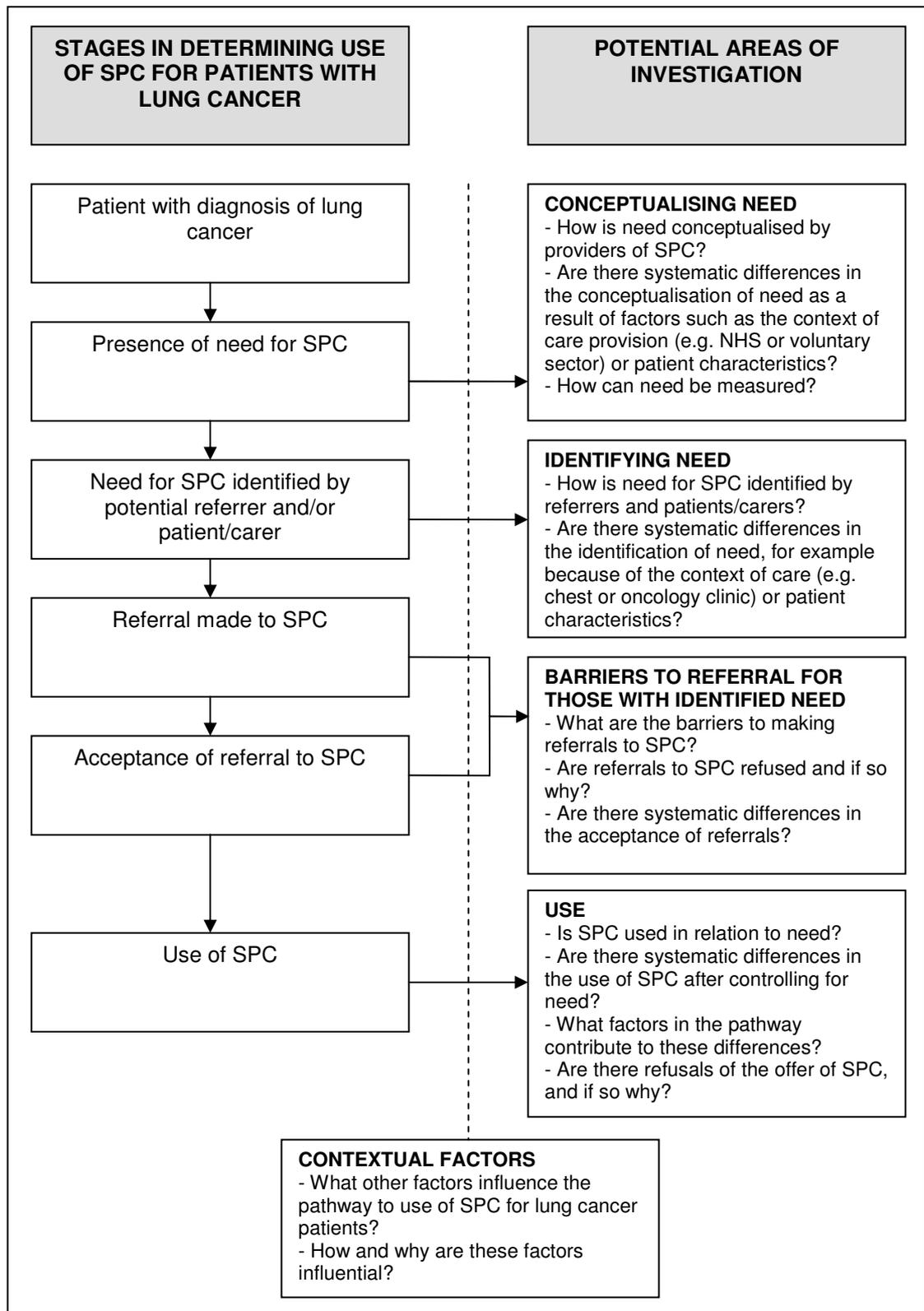


Figure 3.3 The pathway to use of SPC and key research areas

Following this schema, four specific objectives for this study were derived:

1. To explore providers' conceptualisations of need for, and factors influencing use of, SPC for cancer patients.
2. To explore existing methods and instruments which may be used to identify and measure need for SPC in lung cancer patients.
3. To measure use of SPC services in younger versus older lung cancer patients, in relation to need.
4. To examine demand and supply side factors influencing referral to and uptake of SPC services in lung cancer patients.

The suitability of mixed methods

Mixed methods approaches are ideally suited for research with multiple, inter-related objectives. The objectives above have very different requirements, exploring, locating and appraising, and measuring different aspects of the problem; namely, whether there are systematic differences in the use of SPC services, and if so why. It was apparent that (a) each objective required different methods, but also that (b) each objective could not be achieved in isolation. That is, data generated for each objective would be required to feed into other objectives. The utility of mixed methods approaches in answering this overall research question was therefore related both to complementarity (using results from one method to elaborate or clarify results from another method) and development (using results from one method to develop or inform the other method). This will be detailed further below.

Approach taken

This research is situated within a pragmatic epistemology. Pragmatism rejects the notion that knowledge represents reality or, alternatively, that

reality is constructed entirely through social interaction (and thus, as per social constructivist perspectives, there are multiple social realities with their own knowledge which may only be fully understood from within).

Pragmatism asserts that we cannot (and should not) wish to know whether our beliefs correspond with an independent reality. However, as it is at least possible to provide objective criteria to enable a distinction between which beliefs are true or false at that time, the purpose of research is to provide such validation for our beliefs. So, pragmatic inquiry is concerned with examining the strength of the arguments underpinning a particular belief, based on empirical evidence.

Pragmatism does not adhere to the idea that there are fundamental epistemological divides between techniques concerned with human experience and those concerned with 'facts'. All forms of inquiry may be used to add to our body of knowledge (that is, our system of justified beliefs). In this way, and as discussed previously, pragmatism is a natural partner for mixed methods research.

Study design

Study design in mixed methods research has been defined as encompassing the procedures for collecting, analysing and reporting research.²⁰⁸ To address every aspect of the research question, the study design was conceptualized in three inter-related phases [Figure 3.4].

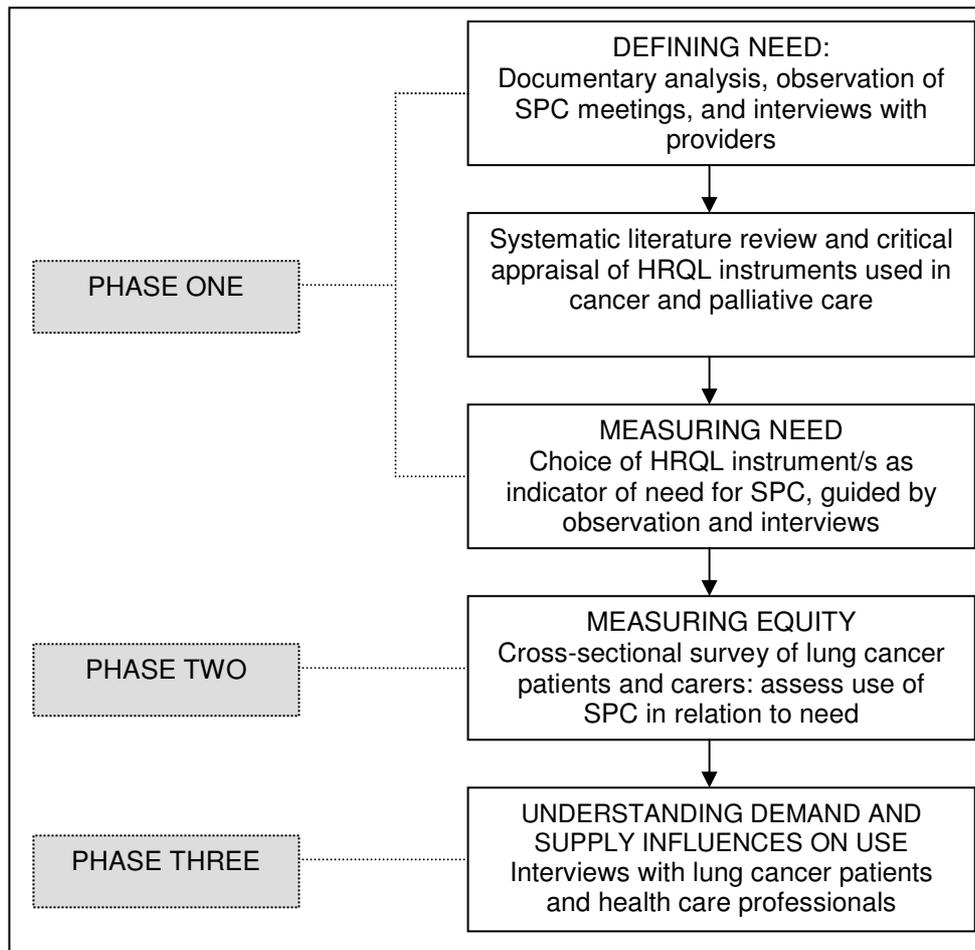


Figure 3.4 The three-phase study design

In the terminology of mixed methods approaches, the study was a sequential ‘qual → quan → qual’ design using a variety of methodologies (ethnographic approaches, systematic reviewing and survey research) and methods (qualitative observation, interviews, systematic literature review, and questionnaires). In the first phase of work, I explored the perspectives of SPC providers on need for their services. Building on this work, I then located and appraised established instruments used to measure HRQL to devise a valid method for measuring need (objectives 1 and 2). In the second phase, I used a cross-sectional survey to investigate whether referral to SPC services by lung cancer patients varied according to age, after controlling for their need for this care (objective 3). Finally, in a third phase I planned to examine

both demand side (patient) factors and supply side (health service) factors which may influence referral to, use of and/or need for SPC (objective 4). For reasons which will be explained in greater detail below, this third phase of work was not undertaken. However, as it formed an integral part of plans for addressing the research question in full, I continue to show its envisaged place within the overall design in this chapter.

A vital aspect of mixed methods research is integration at all stages of the study, with quantitative and qualitative approaches informing and drawing on each other. Figure 3.5 provides details of the study design, and highlights the inter-relationships between the three planned phases of this study at the level of design, method and analysis. As this figure demonstrates, there are six key relationships between the different methods, determined *a priori*, demonstrating both development and complementarity:

1. Results from a thematic analysis of phase one data (based on documents, qualitative observation and interviews) were used to finalise the design of phase two (cross-sectional survey). For example, results from phase one determined that carers, and not just patients, should also be surveyed.
2. Results from a content analysis of phase one data were used to guide selection of the most suitable HRQL instrument to measure need in the phase two survey.
3. The thematic analysis of phase one data was also used to inform multivariable analysis of the survey data by identifying key variables influencing use of palliative care to include in our model.

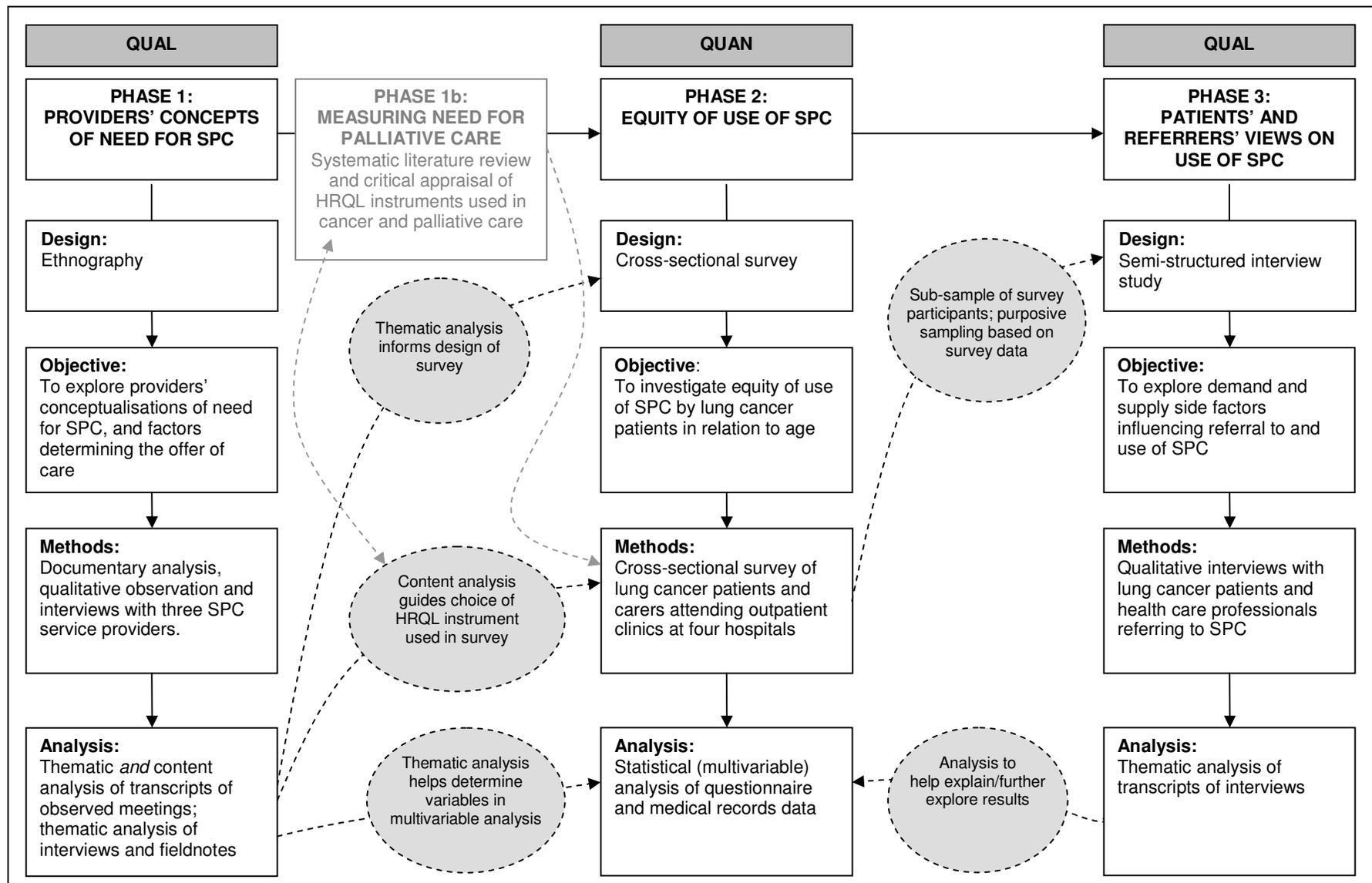


Figure 3.5 Study design and relationships

4. In the planned phase three (interviews with patients and health care professionals) sampling would be guided by data from the phase two survey, for example with patients being selected on the basis of quantitative variables such as HRQL scores.
5. Thematic analysis of phase three data was also planned to feed into a revised multivariable analysis of the survey data in the light of any new themes identified as determining use of SPC.
6. Finally, the results of all phases of the study undertaken were woven together to illuminate differing aspects of the research question, covering concepts of equity, need and use.

The study was designed to take place within one cancer network in England. Cancer networks bring together health service commissioners and providers, the voluntary sector and local authorities to oversee implementation of the NHS Cancer Plan and other policy initiatives within their area. There are 34 cancer networks in England, each covering a population of between one and two million people. The decision to conduct the study within one cancer network was taken to allow me to develop an in-depth understanding of referral procedures and service use across an entire organizational system. Cancer networks routinely use standardised referral procedures and documentation across the Trusts within their domain, and thus provide a stable environment in which to study variations in referral and use of services. A detailed description of the chosen cancer network is given in Chapter 4.

As outlined above, the study was planned with three inter-linking phases to address differing facets of the research question. Phase three, interviews with a purposive sample of lung cancer patients and their health care professionals, was planned to take place immediately after phase two. I have

discussed this final qualitative phase to demonstrate how the study was originally conceived, and the utility of linking quantitative and qualitative approaches and data across all aspects of the research question. The documentation for this phase was drawn up and ethical and research governance approval obtained. However, for the personal reasons outlined in the preface to this thesis, phase two data collection was interrupted, delaying the completion of recruitment to the survey. To achieve a comprehensive and rigorous analysis of data from the first two phases of the study within the time available, the decision was taken not to go ahead with the final phase of work.

Summary

Mixed methods research is an emerging discipline, but one that offers an appropriate and useful approach to many health services research questions. The philosophical and theoretical foundations of mixed methods are open to ongoing debate and development. This necessitates clarity about the philosophical stance (such as pragmatism) taken within a project. Clarity, too, is required to deal with logistical and practical considerations inherent within mixed methods approaches, particularly the combining of inferences from quantitative and qualitative data. Within this study, mixed methods were used to approach the question of equity of use of SPC services. By combining different methods (in this case, ethnography, systematic review, and survey techniques) I was able to devise a thorough investigation of the issues at hand, exploring, measuring and assessing the need for and use of SPC in a particular patient group.

The central concerns of this thesis, theoretical and conceptual, are inevitably contested and fluid. Dimensions of and debates about equity, need and use, pragmatism, and age, have been considered and dealt with in this and the

previous chapter. The next section returns to more concrete ground to provide the practical context in which the more abstract concerns are situated. In the following chapter I give a detailed description of the setting of the study, and the clinical subject matter at hand: the nature of SPC, and the diagnosis, prognosis, and treatment of lung cancer.

Chapter 4

The study in context: specialist palliative care, lung cancer, and the research setting

*The setting holds the key: met out of context
A face is nameless, or if daily seen,
Confused in memory by its many frames.*

*So, though we treat the landscape as a background,
Without it we are – nowhere.*

Anne Ridler. 'Leaving Ringshall: A quodlibet of voices in one self' ²⁰⁹

The theoretical and practical context within which a study takes place is a key influence both on the results obtained, and on interpretation of those results. Detailed study development takes place with reference to the area in which it is to be conducted. At a study's conclusion, reflections on bias and generalisability must be made with consideration of how the data were generated. To provide a framework within which results may be considered, a summary of palliative care, lung cancer and the study setting is provided within this contextual chapter.

Firstly, I focus on palliative care. A brief overview of the development of palliative care and key current debates is given, including the distinction within the UK between generalist and specialist palliative care. Evidence of effectiveness of SPC, and patient experiences of receiving such services, are summarised. Next, I turn to consider lung cancer, including the different types of lung cancer and the epidemiology of this disease. A brief explanation of the treatment options for lung cancer is given, highlighting the important role of palliative treatment in the context of poor prognosis

and high symptom burden. Finally, I describe the setting in which this study took place. I start with an overview of the geographical area and its population, including the epidemiology of cancer and lung cancer within the region. I then outline the lung cancer and palliative care services available for patients within the study setting, and the inter-relationships between these. Figures reported are those most relevant to the time period during which this study was conducted, where available.

4.1 Specialist palliative care

*In the midst of caring for people who are dying, we are also celebrating life in all its richness and variety.*²¹⁰

The development and definition of palliative care

Palliative care is a relatively recent phenomenon, a discipline whose research and practice base is still developing from its origins in the UK in the 1960s. The foundation of this now-worldwide movement is traditionally ascribed to the original vision of one woman, Dame Cicely Saunders. Saunders died in 2005 aged 87 at the hospice she founded in 1967, St Christopher's, in Sydenham, South London. At this, the first 'modern hospice', end of life clinical care, teaching and research were combined for the first time with the aim of improving relief of cancer patients' symptoms, both physical and emotional. Previously, whilst there were a number of hospices caring for the dying (usually established and run by religious foundations), the focus was on providing nursing care alone for those in the final stages of life.

The establishment of an extensive research programme at St Christopher's led to influential advances in care, particularly in the area of terminal pain control. From the 1970s onwards, the principles of 'hospice care' began to be rolled out into other settings, including hospitals and the community.²¹¹

Whilst the hospice movement had started (and remains) predominantly within the voluntary sector, during this time NHS services were also being developed.²¹² With increased availability and continued developments in practice, a particular philosophy of care coalesced which focused on physical, social, psychological and spiritual support, delivered by a multi-disciplinary team: palliative care.²¹¹ By the late 1980s, palliative medicine was sufficiently developed in the UK that it was established as a subspecialty of general medicine, thereafter becoming a specialty in its own right.

Today, the provision of palliative care is widespread, and is offered on an in-patient basis (in hospitals and hospices), as day care, and as home care for patients in the community. By 2006 in England, Wales and Northern Ireland, there were a total of:

- 288 services providing care in the hospital setting
- 187 inpatient units providing palliative care (with 2774 beds)
- 216 providers of day care services, and
- 295 providers of community care²¹³

All services are expected to meet standards set down in guidelines issued by NICE covering the organisation and delivery of supportive and palliative care for patients with cancer.¹⁹ These guidelines form part of recent Government initiatives to improve the quality of cancer care.¹³ They require providers to work with commissioners to address key recommendations on service co-ordination and approach, and represent a milestone in the regulation and standardisation of minimum palliative care provision.²¹⁴ Palliative care is now a central aspect of UK Government cancer policy, and the development of an end-of-life care strategy has widened this approach to all life-threatening conditions.²⁰

In response to developments both in the UK and other countries, a formal, internationally accepted, definition of palliative care was first offered by the WHO in 1989. This has been revised through the years, and the 2002 version states that:

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, psychological and spiritual. ²¹⁵

Other definitions of palliative care have been offered; all focus on the holistic nature of palliative care and the aim of improving quality of life. For example, one definition of palliative nursing states that:

All life-threatening illnesses – be they cancer, neurological, cardiac or respiratory disease – have implications for physical, social, psychological and spiritual health, for both the individual and their family. The role of palliative nursing is therefore to assess needs in each of these areas and to plan, implement and evaluate appropriate interventions. It aims to improve quality of life and to enable a dignified death. ²¹⁶

The NICE guidance on supportive and palliative care adopts a WHO definition of the nature of palliative care, ²⁷ but additionally it divides palliative care into two types: *generalist* and *specialist*. ¹⁹

Generalist and specialist palliative care

Under the WHO definition, *all* patients with cancer and other life-threatening illnesses could be said to have an ability to benefit from palliative care. This very broad formulation of need, based on diagnosis, is commonly employed in studies of use of palliative care. ^{119;123;124} However, within the UK in recent years the provision of palliative care has increasingly been distinguished as two types of care – that provided by generalists in

their everyday work (such as GPs and district nurses), and that provided by specialists (such as consultants and clinical nurse specialists in palliative medicine).²⁸ In this model, specialists offer care only to particular patients with more complex and persistent problems, which generalists may not have the skills to deal with effectively.¹⁹

The National Council for Palliative Care (NCPC) has set out the components of a SPC service, as provided by a dedicated multidisciplinary team.²¹⁷ These teams should include palliative medicine consultants, palliative care clinical nurse specialists, social workers, physiotherapists, occupational therapists, dieticians, pharmacists, and staff members qualified to offer spiritual and psychological support. According to the NCPC, SPC services will:²¹⁷

- Assess, advise and care for patients and families in all care settings, including hospitals and care homes.
- Offer specialist in-patient facilities (in hospices or hospitals) for patients who may benefit from specialist input.
- Offer home support for patients with 'complex needs' who would like to be cared for at home. Specialist services will work alongside GPs and district nurses, most commonly as an advisory service. Some services will offer more intensive, hands-on nursing and medical care, usually referred to as 'hospice at home'.
- Offer day care facilities to assess and review patients' needs, provide physical, psychological and social interventions, and frequently offer creative and complementary therapies.
- Provide advice and support to all the people involved in a patient's care.
- Provide bereavement support for the people involved in a patient's care following the patient's death.

- Offer education and training in palliative care.

Generalist care, by contrast, may be referred to as the provision of a 'palliative care approach' by non-specialists in the field. These might include hospital doctors and nurses, GPs and other members of the primary care team. Whilst some of these health care professionals, particularly oncologists, GPs and district nurses, may have regular contact with patients with advanced cancer, such care does not form the major component of their professional role. As set out in the NICE guidelines, generalist palliative care encompasses:¹⁹

- information for patients and carers, with 'signposting' to relevant services
- accurate holistic assessment of patient needs
- co-ordination of care teams in and out of hours and across boundaries of care
- basic levels of symptom control
- psychological, social, spiritual and practical support
- open and sensitive communication with patients, carers and professional staff.

The guidance stresses that generalists must seek advice from specialists when necessary. However, in spite of the division into generalist and SPC, and clarification of what these both involve, there is little guidance given as to *which* patients will require or benefit from specialist intervention.

Evidence of effectiveness of specialist palliative care

The effectiveness of SPC in improving patients' and carers' quality of life, managing pain and other symptoms and addressing psychological, social

and spiritual concerns has been debated in the light of limited research evidence.²¹⁸ The challenges of conducting randomised controlled trials (RCTs) within palliative care have been well documented; problems include poor recruitment, patient attrition, ethical concerns and a lack of rigorous outcome measures.²¹⁹⁻²²¹ With few RCTs completed, systematic reviews of the impact of SPC have included a large proportion of observational studies.^{218;222} Whilst drawing attention to the lack of high quality studies on effectiveness, these reviews have concluded there is some evidence that SPC has a small but positive effect on the control of pain and other symptoms, and on patient satisfaction, when compared to conventional care.^{218;222} A more recent systematic review of research evidence conducted to inform the NICE guidance concluded that SPC improved outcomes for cancer patients across all settings – at home, in hospital and in hospices.²²³ However, its impact in areas such as psychological and spiritual support is less well documented.

SPC defines itself as being aimed at informal carers as well as patients. Meeting the needs of both patient and family may be challenging, but it is regarded as a fundamental aspect of the role of SPC providers.²²⁴ Again, however, evidence on the effectiveness of interventions in cancer and palliative care to support informal caregivers is limited.²²⁵

Patient experiences of specialist palliative care

There is limited research on patients' perspectives of SPC. Studies tend to be small scale and are frequently opportunistic. However, from research which has been conducted it is clear that palliative care is frequently perceived by patients and carers to focus on terminal care and death; as a result patients report being upset or shocked by their own referral to the service.^{226;227} Yet, once they are receiving care from a SPC team, patients quickly come to value

their specialist knowledge of symptom, especially pain, control.²²⁸ Patients often perceive that SPC teams have more time to devote to their care, offering 'someone to talk to' about their experiences.²²⁹ Building up a relationship with key SPC staff, and knowing that they can contact someone for advice at any time, leads to a feeling of security and safeness for patients which in many cases had previously been lacking.²²⁸ As a result of these factors, satisfaction with SPC services is often high.^{230;231}

Current debates in palliative care

Today, palliative care is firmly established as a medical and nursing specialty, and integrated within primary and secondary care services. Further development of palliative care centres on two main issues – a move away from terminal care to care at all stages of disease, and a widening of focus from providing cancer care alone to caring for patients with other life-threatening illnesses.^{215;232} The first debate is briefly highlighted here as it impacts on concepts and definitions of need for palliative care as addressed in this thesis.

Following the establishment of palliative care as a specialty in its own right, practitioners began to consider how this approach may benefit cancer patients at all stages of the disease. Empirical studies showed that cancer patients may have need for symptom, psychological and other support (as provided by the palliative care approach) from diagnosis rather than only in the end stages of disease.¹⁰⁵ Greater understanding of symptom development and control led to the conclusion that problems at the end-of-life may have their beginnings much earlier in the disease trajectory.²¹⁵ Palliative interventions could therefore benefit patients with progressive, life-limiting illnesses alongside attempts at curative treatment.²³³

The move from a 'traditional' end-of-life care concept to a more integrated approach has been shown diagrammatically [Figure 4.1].²³⁴ Incorporating palliative care earlier in the disease trajectory offers two possibilities; (i) the use of a generalist palliative care approach by all medical staff from the diagnosis of cancer and/or (ii) the involvement of SPC providers to provide advice and support for the patient and family from diagnosis or shortly afterwards. This model is now widespread within the literature, and is commonly referred to as the 'Sheffield' model after its place of origination.²³⁵ However, whether this theoretical view is reflected in clinical practice is questioned.²³³ SPC providers may become involved only at the switch from curative to palliative interventions, and when there is a recognition a patient has a limited time left to live. For example, in the USA the criteria for the receipt of palliative care under Medicare for the over-65s remains the certification by two clinicians that life expectancy is six months or less.²³⁶

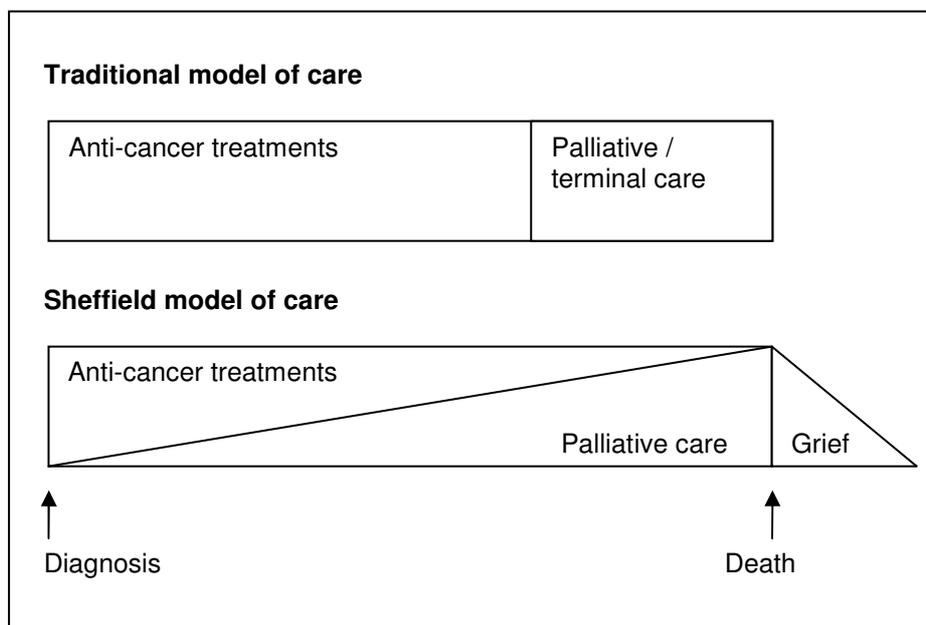


Figure 4.1 Changing views of palliative care

SPC has developed rapidly over a short period of time, although there continues to be a deficiency of evidence of effectiveness and a lack of clarity over its content and future direction.²³³ In particular, whilst the organisation and nature of SPC services are clearly agreed, the specific patients who may need this type of care are poorly defined in policy and literature. For those who do receive such services, palliative care enjoys a high reputation.

As a result of the heavy symptom burden of lung cancer, such patients are often seen as ideal candidates to receive SPC.²³⁷ The following section briefly summarises the nature of this disease. It highlights its high incidence and poor prognosis, considers the treatments on offer (both curative and palliative), and gives a brief insight into the reported experiences of people diagnosed with lung cancer.

4.2 Lung cancer

*We still have a considerable way to go until we have achieved optimal management for the patient with lung cancer.*²³⁸

Development, types and symptoms

Primary lung cancer is the development of a malignant tumour within the lungs. It is divided into two main types, which behave and respond to treatment in different manners. These are small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). About 25% of diagnosed lung cancers are SCLC, and 75% NSCLC (²³⁹ p. 63). NSCLC is a grouping of three cancers, divided according to the histology of the tumour:

1. Squamous cell carcinoma
2. Adenocarcinoma
3. Large cell carcinoma

As all lung cancers develop, they may cause a variety of symptoms including:

- Persistent or worsening cough
- Dyspnoea (shortness of breath)
- Chest pain
- Haemoptysis (coughing up blood)
- Hoarseness
- Recurrent chest infections
- Fatigue
- Weight loss

Research suggests that lung cancer patients experience a high symptom burden.²⁴⁰ One study found that lung cancer outpatients reported a greater degree of symptom severity than patients with other cancer diagnoses.¹⁰⁶ Pain, fatigue and dyspnoea have been identified as causing particularly high levels of distress.^{241;242} Symptoms are frequently compounded by the high prevalence of comorbidity, especially cardiovascular diseases and chronic obstructive pulmonary disease (COPD), amongst patients with a diagnosis of lung cancer.²⁴³

Incidence and mortality

In 2006, there were a total of 39,027 reported cases of lung cancer within the UK (22,381 (57.3%) in men and 16,646 (42.7%) in women), accounting for 13% of all cancer diagnoses.²⁴⁴ Incidence is greater in the north of the UK, and highest in Scotland, reflecting historical variations in smoking rates across the country.

Lung cancer is primarily a disease of older adults, with 85% of lung cancer cases diagnosed in people aged 60 and over. Peak incidence falls between 75 and 79 for both men and women [Figure 4.2].²⁴⁴

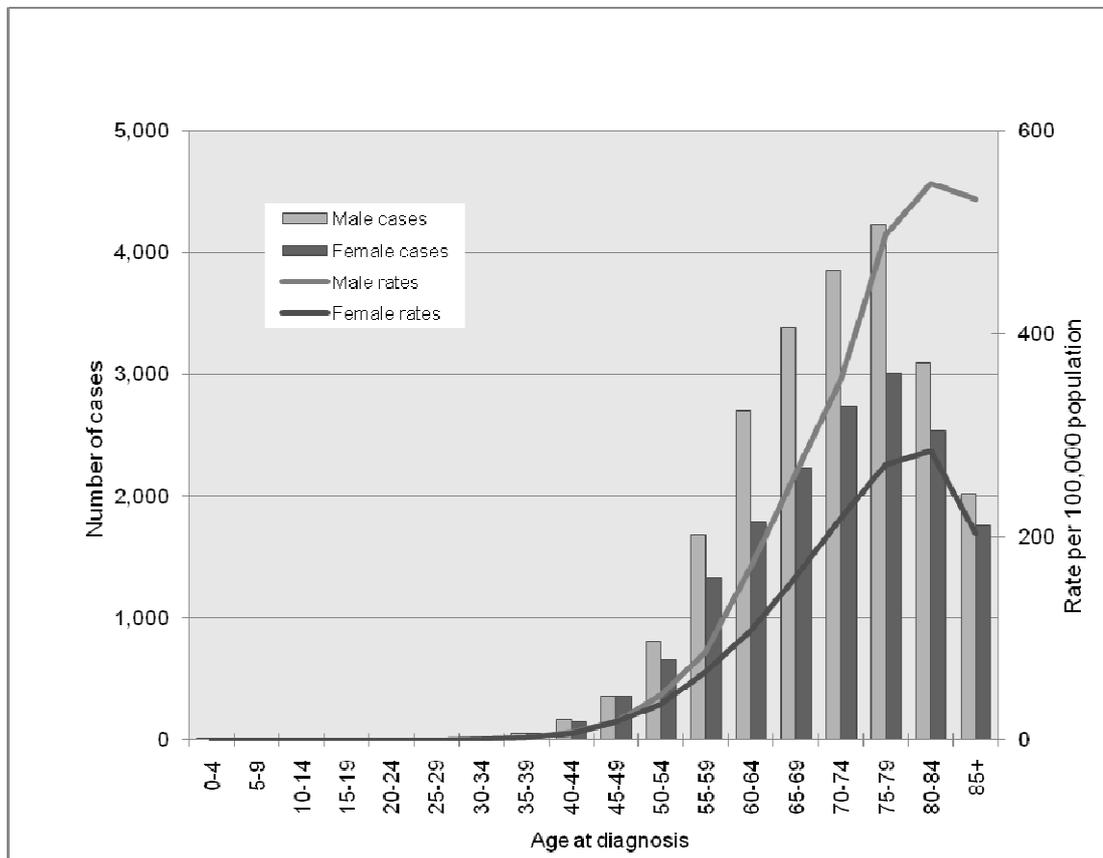


Figure 4.2 Lung cancer incidence and age specific incidence rates, by sex, UK 2006

Lung cancer has a high mortality rate, causing 22% of all cancer deaths in England and Wales.²⁴⁵ It is the most common cause of cancer death in men, (24% of all cancer deaths) and the second most common cause of cancer death in women (19% of all cancer deaths), following breast cancer.²⁴⁵

Staging and treatment

NSCLC is staged using the TNM system:

- T to indicate the size and location of the primary tumour

- N to indicate spread to regional lymph nodes
- M for distant metastasis

These are then classified into stage groupings ranging in severity from stage I to IV. Whilst SCLC can in theory also be classified using the TNM system, in practice it is grouped into two stages, limited or extensive disease. Limited disease is defined as being where all detectable tumour can be encompassed within a radiotherapy port. Extensive disease includes patients with metastatic lesions in the other lung, and those with distant metastatic involvement.

NICE guidelines on the diagnosis and treatment of lung cancer set out recommended treatment approaches.²³⁷ Options include surgery, radical radiotherapy, palliative radiotherapy, chemotherapy, and best supportive care. Full details of standard treatment regimes are in Appendix I.

Which treatments do patients receive?

Accusations of ‘therapeutic nihilism’ (a reluctance to investigate or treat) have been levelled at physicians caring for lung cancer patients, in part attributed to the typically older age of lung cancer patients at diagnosis.²⁴⁶ However, whilst surgery rates in lung cancer remain low (in the main due to the high proportion of patients who are diagnosed at later stages of the disease), the use of chemotherapy and radiotherapy has increased in recent years.²⁴⁷ In London in 2004, 11% of patients with lung cancer were reported to have received surgery; 23% received chemotherapy and 25% received radiotherapy in the first six months following diagnosis.²⁴⁸ For 23% of patients, no treatment was recorded. Slightly different figures were derived from an audit of lung cancer patients in one cancer unit in the UK from 1998 to 2001 [Table 4.1]; for this earlier time period, these show that the most

common approach for NSCLC patients was best supportive care only (defined in this instance as excluding the receipt of any treatment).²⁴⁹

Table 4.1 Initial treatment for lung cancer in a UK cancer unit, 1998-2001 ²⁴⁹	
NCSLC	n (%)
Surgery	84 (12)
Radical radiotherapy	24 (4)
Palliative radiotherapy	225 (32)
Chemotherapy	57 (8)
Best supportive care	255 (36)
Missing data	57 (8)
SCLC	n (%)
Palliative radiotherapy	6 (5)
Chemotherapy	75 (56)
Best supportive care	28 (21)
Missing data	24 (18)

With a frequently short survival time and heavy symptom burden, SPC is argued to play a central role in the management of lung cancer patients and families.²⁵⁰ Symptoms amenable to SPC intervention which are particularly prevalent in lung cancer patients include dyspnoea, pain, and fatigue.^{242;251;252} Whilst one study concluded that 83% of lung cancer outpatients reported one or more issues which could benefit from SPC care,¹⁰⁶ the proportion of patients who actually receive such services is likely to be much lower.²⁵³

Survival

Lung cancer is frequently diagnosed at a late stage. Only a small proportion of patients are therefore deemed eligible for curative treatment, and overall survival rates are subsequently low. In the UK, about 25% of patients diagnosed with lung cancer are alive one year later, and only 7% are alive at five years.²⁵⁴

Survival is related to stage of disease at diagnosis and the treatment patients receive. A review of lung cancer patients diagnosed between 1998 and 2001 at one UK cancer centre reported median survival for NSCLC patients as being 18.1 months for stage 1 patients, 13.4 months for stage II, 7.4 months for stage III, and 2.1 months for stage IV.²⁴⁹ When analysed by treatment received, the following median survival times were reported:

- Surgery – 52.4 months
- Radical radiotherapy – 21.6 months
- Palliative radiotherapy – 6.2 months
- Chemotherapy – 8.3 months
- Best supportive care only – 1.8 months.

Even with the receipt of curatively aimed treatment such as surgery, survival may be poor. One study reported that five year survival following surgery varies widely according to stage of disease, with reported rates of 69% in stage IA, 52% in IB, 45% in IIA and 33% in IIB.²⁵⁵ For patients with stage I and II disease receiving radical radiotherapy, a systematic review reported overall five-year survival of only 17%, substantially worse than patients receiving surgery.²⁵⁶

Survival also varies with patient age, with five year survival in males falling from 9% at aged 40-49 to 2% at ages 80 and above, and in females from 13% at 40-49 to 1% at ages 80 and above [Figure 4.3].

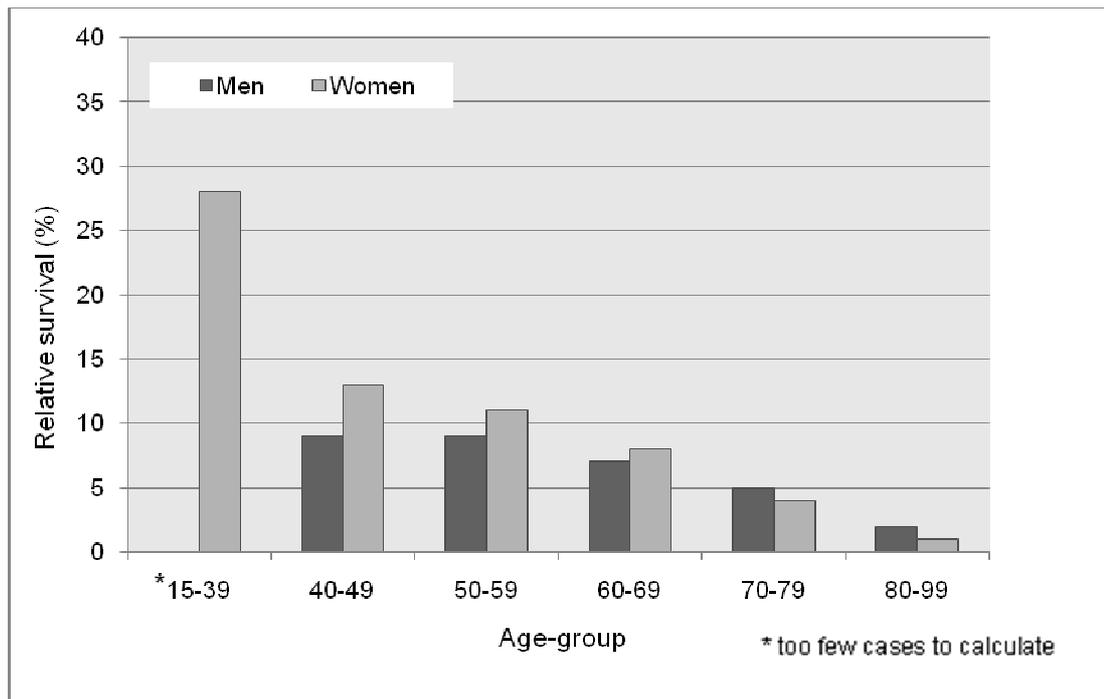


Figure 4.3 Five year relative survival by age, England and Wales, adults diagnosed 1996-1999 and followed up to the end of 2001 ²⁵⁴

Patient experiences

The fear and the anxiety don't go away. There isn't a day when I don't think, you know, "I've got cancer, why did this happen? This is horrible, it's terrible. What does it mean in terms of life expectancy?"

54 year old male diagnosed with SCLC, recounting his experiences for patient information website Healthtalkonline. ²⁵⁷

Lung cancer has been referred to as the 'Cinderella of common solid tumours', as despite its high incidence and poor prognosis it is one of the least-researched and least-discussed cancers. ²⁴⁶ This dearth of understanding extends to the experiences of people diagnosed with lung cancer. Studies which have been conducted in this area are summarised briefly below.

Delays in the diagnosis of lung cancer, and the subsequent prevalence of advanced disease at diagnosis, have long been a source of particular concern.²⁵⁸ A small exploratory UK study found that a median of 7 months passed between patients' first recalled changes in health and the onset of the symptom or event that finally led them to seek medical care and receive a diagnosis of lung cancer.²⁵⁹ Reasons for the delay in seeking care included uncertainty over what may be normal, with the attribution of symptoms to 'everyday causes', or to other co-morbid diseases.²⁶⁰ Additionally, patients had either not considered the possibility of lung cancer, or had suppressed this as a possibility.

Once patients have sought help, reactions to a diagnosis of lung cancer may include shock, relief or resignation.²⁶¹ Following diagnosis, patients may feel uncertain about where they 'belong' – not yet safely under the care of the hospital team, but no longer the responsibility of the GP. Such feelings can cause acute anxiety and distress for both patients and carers; feelings that may be repeated during the gaps which occur between completing treatment and subsequent follow-ups.²⁶² Further, perceived stigma attached to the diagnosis of lung cancer as a result of its strong association with smoking may cause anxiety in patients concerned they will be denied access to care.²⁶³

As previously highlighted, many lung cancers are diagnosed only at an advanced stage. Treatment options may be limited, and progression rapid. As Deborah Hutton, a women's health journalist, wrote shortly before her death from NSCLC in July 2005 aged 49:

*It didn't take long to find out that in the world of advanced cancer, stage IV is as bad as it gets. There is no stage V.*²⁶⁴

Hutton, a fitness and health fanatic who had smoked briefly as a young adult, survived for less than eight months from diagnosis, during which time she received six cycles of chemotherapy to little effect.

The final section of this chapter moves away from clinical considerations to focus on the setting in which my research took place. I firstly outline reasons for the choice of study location, and the strengths and limitations as a result of this. I then provide some contextual information on the setting, including its geography and population. Next I consider the morbidity and mortality profile of the population, particularly with reference to cancer and lung cancer. Finally, the palliative and cancer care systems within the area are explained.

4.3 Study setting

*Cancer networks will work together to develop strategic service delivery plans to develop all aspects of cancer services – prevention, screening, diagnosis, treatment, supportive care and specialist palliative care. They will agree common protocols and service patterns to tackle variations and to make best use of resources.*¹³

Rationale for choice of study setting

The study took place within one cancer network in London, England. Cancer networks were first proposed as the most appropriate structure for the delivery of cancer care by the Calman-Hine report, published in 1995.²⁶⁵ This influential report, commissioned by the Government to develop a policy framework for commissioning cancer services, envisaged a network of providers from primary care, through Cancer Units in District General Hospitals, to Cancer Centres in major teaching hospitals, all working together to deliver a uniform standard of care. Cancer networks were subsequently established as the organisational structure for the

implementation of the NHS Cancer Plan and other policy initiatives within each region.¹³ They bring together health service commissioners and providers, the voluntary sector and local authorities within a defined area. Originally tasked with reviewing current service provision, networks now focus on developing services in line with Government targets and expectations. Currently there are 34 cancer networks in England, each covering a population of between one and two million people.

I decided to confine the study to one cancer network to promote an understanding of service use across an entire organizational system. Within networks, health care professionals use standardised referral forms for cancer and palliative care services with reference to criteria for making such referrals. This provides a degree of organisational cohesiveness within which investigations of variations in use may take place.

The participating cancer network covers a population of about 1.5 million across six Primary Care Trusts (PCTs) in London. It was purposively chosen as the study setting due to its diverse population in terms of age, ethnicity and deprivation, its mix of both urban and suburban areas, wide variations between PCTs in the provision of cancer and SPC services, and a high incidence of lung cancer. Despite these variations, it operates a standardised referral system for cancer and palliative care services. Additionally, I had developed strong links and a good understanding of the cancer system within the network as a result of previous research.

The restriction of the study to one cancer network may limit generalisability of the study findings as a result of the unique service provision and population characteristics within the area. Whilst the network covers both urban and suburban areas, it does not include any rural settings. The referral

to and use of palliative care within rural settings may differ markedly, particularly for patients at home, as lengthy travel distances to isolated communities may lead to different organisational approaches to care being adopted. However, as the provision of SPC has largely developed within the voluntary sector, widespread variations in care exist across all areas with little reference to whether services are urban, suburban or rural. For example, some rural areas in England are exceptionally well provided for palliative care as a result of local fundraising and commitment to establishing such services, whilst some urban areas have very patchy coverage.¹³

An additional consideration for generalisability is the population contained within the network, discussed in detail below. Differing age structures of the population between this network and other regions, and variations in other key socio-demographic variables including deprivation, must be considered when extrapolating findings.

Despite the potential restrictions on generalisability, the focus on one cancer network is beneficial in containing the study within one system of care with standardised guidelines for referral. Additionally, the confinement of the study to one geographical area enhanced the rigour with which data collection could be conducted within the available study resources.

Geography and socio-demographics of the cancer network

The participating network comprises six PCTs, all of which are coterminous with six Local Authority boundaries. According to the population estimates for mid-2005, the area had a total population of 1,524,600.²⁶⁶ Whilst population numbers are relatively evenly spread across the six PCTs within the area, the characteristics of their populations vary widely. In particular,

the three inner London PCTs within the network have a lower proportion of older residents compared to the London average, and a higher proportion of residents from black and ethnic minority groups [Table 4.2]. One explanation for the relatively young population structure of the inner London PCTs is the high level of migration within these areas.²⁶⁷ Index of Multiple Deprivation (IMD) scores also reveal wide differences, with four of the PCTs being some of the most deprived boroughs in England.

Table 4.2 Overview of PCTs					
PCTs	Location	Population at census 2001	Proportion of over 75s ¹	Minority ethnic population ²	Index of Multiple deprivation 2004 ³
A	Inner	266,169	4.2%	31.6%	13
B	Inner	244,866	4.8%	37.0%	12
C	Inner	248,922	5.3%	34.1%	38
D	Outer	218,307	7.4%	8.6%	216
E	Outer	295,532	8.2%	8.4%	252
F	Outer	214,403	6.5%	22.9%	23

[1] Estimates from the 2001 census. Proportion of 75s and over: England 7.5%, London 5.9% (Inner London 4.7%, Outer London 6.6%)

[2] Estimates from the 2001 census. Percentage is that of all other categories apart from White. (England 9.1%, London 28.8%)

[3] IMD 2004 rank of average of ward ranks - out of 354 districts, 1 = most deprived

Mortality and morbidity in the cancer network

Life expectancy for both males and females is lower than the England average in four of the PCTs [Figure 4.4]. As a result of their poor population health and high deprivation levels, these are designated part of the Spearhead group of local authorities and PCTs.⁹⁶ This group, set up to accelerate reductions in health inequalities in England as a result of the Public Health White Paper Choosing Health,⁶ initially comprised 88 PCTs in the bottom fifth in England for 3 or more of the following indicators:

- Male life expectancy at birth
- Female life expectancy at birth

- Cancer mortality rate in under 75s
- Cardiovascular disease mortality rate in under 75s
- Index of Multiple Deprivation 2004 (Local Authority Summary), average score

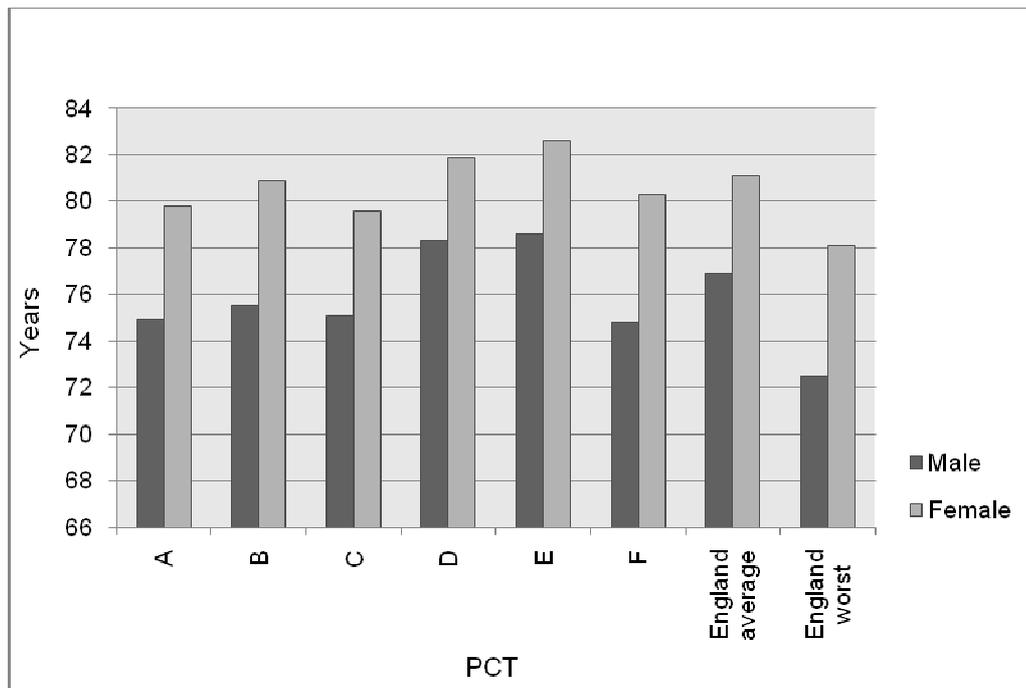


Figure 4.4 Life expectancy in the cancer network

Table 4.3 shows key indicators for population health in the area. As would be expected in the Spearhead PCTs, these are all below the England average for the number of deaths from smoking, and the number of early deaths (below age 75) from cancer.

Table 4.3 Key health indicators for PCTs			
PCTs	Deaths from smoking^a	Early deaths: cancer^b	Compared to England average
A ²⁶⁸	280.7	133.1	↑ above
B ²⁶⁹	293.5	126.1	↑ above
C ²⁷⁰	296.2	140.5	↑ above
D ²⁷¹	218.8	111.0	↓ below
E ²⁷²	201.7	108.9	↓ below
F ²⁷³	304.1	138.9	↑ above
England average	234.4	119.0	-
England worst	366.5	168.0	-

[a] Directly age-standardised rate/100,000 population aged 35 or over, 2003-2005

[b] Directly age-standardised rate/100,000 population, under 75s, 2003-2005

Cancer incidence and mortality

There were a total of 5,762 cancer registrations in the network in 2004, a rate of 406.4 per 100,000 population in males and 341.6 per 100,000 population in females.²⁴⁸ Lung was the second most common cancer in males in the region, behind prostate but ahead of colon – together these three accounted for 44.7% of all cases. Lung was also the second most common cancer in females, with breast the most common and colon the third most common, together accounting for 49.1% of all cases [Table 4.4]. These figures echo the most common cancers in England in 2004; breast, lung, colorectal and prostate.

Table 4.4 Cancer registrations in the network 2004 * 248					
Female			Male		
Cancer site	Cases	Rate	Cancer site	Cases	Rate
Breast	886	114.3	Prostate	576	84.7
Lung	354	38.9	Lung	479	69.2
Colon	200	21.1	Colon	209	30.3
Uterus	140	18.3	Head and neck	148	22.7
Ovary	122	14.8	Rectum	150	21.8
Rectum	109	12.3	Bladder	124	17.4
Head and neck	93	11.1	Non-Hodgkin's lymphomas	119	17
Non-Hodgkin's lymphomas	88	10.5	Stomach	91	12.2
Pancreas	93	9.6	Pancreas	79	11.8
Cervix	71	8.6	Oesophagus	75	11.3
Stomach	65	6.1	Melanoma of skin	45	6.1
Melanoma of skin	52	5.8	All	2830	406.4
Oesophagus	49	4.6			
Bladder	49	4.5			
All	2932	341.6			

* Numbers of registrations and age-standardised incidence rates per 100,000 European standard population.

All-cancer mortality is higher than expected in PCTs D, A, and B [Table 4.5] compared to England as a whole, with Standardised Mortality Ratios (SMRs) for these PCTs of 112, 106 and 115 respectively.

Table 4.5 All cancer mortality in the network 2003 to 2005 (pooled) ²⁷⁴				
Indirectly standardised ratios (SMRs)				
PCTs	Observed mortality	Standardised mortality ratio (SMR)	SMR 95% confidence limits	
			Lower	Upper
A	1257	106	100	112
B	1284	102	97	108
C	1486	115	109	121
D	1583	96	91	100
E	2250	94	90	98
F	1482	112	107	118
Inner London	14198	101	99	102
Outer London	28040	96	95	97
London	42238	97	97	98
England	379580	100	100	100

Lung cancer incidence and mortality

The cancer network has a high overall incidence of lung cancer compared to London and England, although there is great variation within the network. During 2001 to 2003, there were a total of 1,519 registered diagnoses of lung cancer in the network. Standardised registration ratios (SRRs: the ratio of observed to expected registrations in an area multiplied by 100) show that lung cancer incidence was significantly higher than expected in PCTs D, A, and B compared to England as a whole [Table 4.6]. Figures are not currently available separately for NSCLC and SCLC.

Table 4.6 Incidence of lung cancer in the network 2001 to 2003 ²⁷⁴				
Indirectly standardised registration ratios (SRRs)				
PCTs	Observed incidence	Standardised registration ratio (SRR)	SRR 95% confidence limits	
			Lower	Upper
A	240	134	118	152
B	251	136	120	154
C	215	115	100	131
D	267	111	98	125
E	300	89	79	100
F	246	132	116	150
South East London	1519	116	110	122
London	6611	105	103	108
England	55053	100	99	101

Consistent with a raised incidence, lung cancer mortality was also significantly higher than the English average in PCTs F, A, C and B [Table 4.7].

Table 4.7 Lung cancer mortality in the network 2003 to 2005 (pooled) ²⁷⁴				
Indirectly standardised ratios (SMRs)				
PCTs	Observed mortality	Standardised mortality ratio (SMR)	SRR 95% confidence limits	
			Lower	Upper
A	321	131	117	146
B	358	137	123	152
C	325	122	109	136
D	342	98	88	109
E	481	96	88	105
F	364	134	120	148
Inner London	3473	119	115	123
Outer London	5730	94	92	96
London	9203	102	100	104
England	80204	100	99	101

In the network as a whole, one-year survival in lung cancer patients is slightly lower than the overall proportion of patients surviving in London, although this difference is not statistically significant. When survival rates in London as a whole are compared to those in England, a larger proportion of patients are alive at one year post diagnosis, potentially reflecting the greater availability of cancer care in the capital. However, by five years post diagnosis only 6.2% of patients in the network are still alive, the same figure as for England [Table 4.8].

Area	Number of patients	One-year survival ^a			Five-year survival ^b		
		%	95% confidence limits		%	95% confidence limits	
			Lower	Upper		Lower	Upper
Network	2212	25.6	22.4	28.8	6.2	4.4	8.1
London	9385	26.8	25.2	28.3	6.6	5.6	7.5
England	76969	24.2	23.6	24.7	6.2	5.9	6.6

[a] Patients diagnosed 1997-99 (followed up to 31 December 2000)

[b] Patients diagnosed 1997-99 (followed up to 31 December 2004)

Organisation of cancer and palliative care services in the cancer network

There are six acute trusts serving the network. Four are designated cancer units and the remaining two jointly serve as the cancer centre for the network. Cancer units are usually District General Hospitals with a full range of support services for cancer patients, including designated clinics for specific common cancer sites such as lung cancer. Cancer centres offer diagnosis and treatment for all cancers, including rarer cancers referred from cancer units, and also provide specialist diagnostic and therapeutic techniques such as radiotherapy. ²⁶⁵ The cancer network therefore operates on a 'hub and spoke' basis, with the cancer centre providing the most specialised care. More details about the clinics, hospitals and SPC providers which participated in this study are given in chapters 6 and 7.

The cancer network is also part of a Supportive and Palliative Care Network. This umbrella organisation brings together palliative care providers and commissioners to work towards enhancing provision and meeting standards including those set out in the NICE Guidance on Supportive and Palliative Care.¹⁹ Within this area of the palliative care network, there are eleven providers of SPC, although additional services from outside the network area are also used. These can be summarised by setting:

Hospital inpatient care

Each of the six acute trusts operates a SPC team to offer care to hospital inpatients.

Hospice inpatient care

There are three hospices providing specialist inpatient care and other services to parts of the cancer network, with a total of 97 beds.

Home care

A total of seven providers, including three acute trusts, two of the hospices and two stand-alone services, operate SPC community teams to support patients in their own homes within the network.

Figure 4.5 summarises the arrangements for cancer and palliative care service provision within the area.

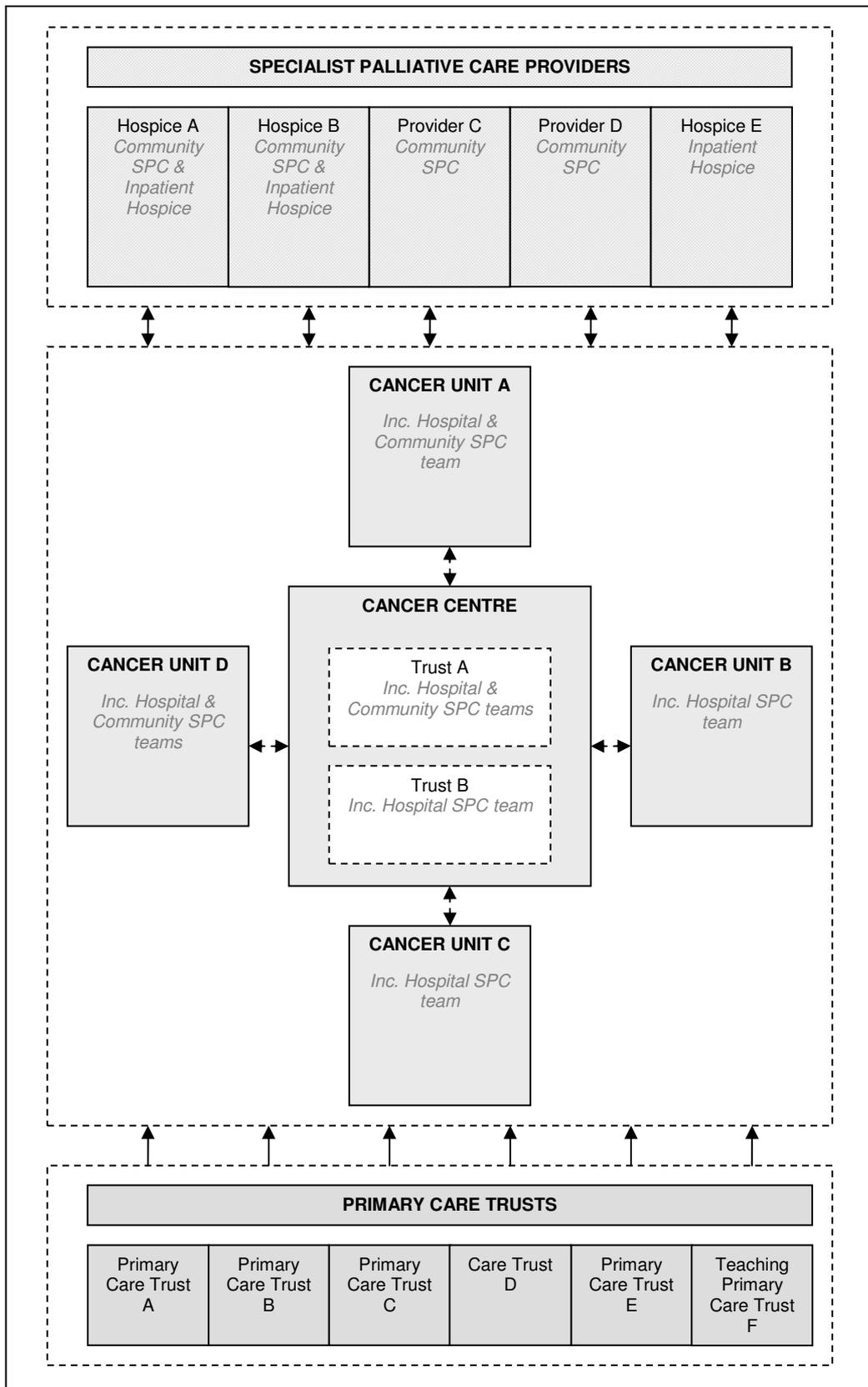


Figure 4.5 The organisation of cancer and SPC in the network

Standardised referral procedures operate across the network for GPs to refer suspected lung cancer patients to a cancer unit or centre, and for all health care professionals to make a referral to one of the SPC services in the area. This requires referrers to complete the relevant referral form; the same clinical and personal details are therefore received by each provider of care. However, there are *not* standardised procedures across SPC providers in how they choose to respond to referrals.

The network is a diverse urban area, encompassing six PCTs with varying levels of deprivation, morbidity and mortality. Cancer mortality, both overall and for lung cancer in particular, is higher than expected. The population is served by a number of different hospitals and palliative care providers, although these work together as a network with common referral procedures for cancer and palliative care services.

Following this summary of the context within which this research project took place, I move on to present findings of the ethnographic study I conducted within three SPC providers in the network. This exploration of how need for SPC was defined and operationalised by providers of care had two broad aims: to understand in greater depth the nature and content of decisions to offer care, and to inform my approach to measuring need within a later study of use of SPC.

Chapter 5

Defining need for specialist palliative care: ethnographic study

*As he came near death things grew shallower for us:
We'd lost sleep and now sat muffled in the scent of tulips, the
 medical odours, and the street sounds going past,
 going away;
And he, too, slept little, the morphine and the pink light the
 curtains let through floating him with us,
So that he lay and was worked out to the skin of his life and
 left there,
And we had to reach only a little way into the warm bed to
 scoop him up.*

Roy Fisher. *As He Came Near Death*.²⁷⁵

Palliative care is defined by the World Health Organisation (WHO) as:

*The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.*²⁷

This statement suggests need for palliative care is a multidimensional concept. In spite of this, studies including palliative care need commonly use narrow definitions – a diagnosis of cancer, or the presence of pain.²⁷⁶ This approach may arise in part due to insufficient consideration of the importance of assessing need to examine equity. Without an effective measure of need, studies of variations in use can only report on inequalities (differences in use) rather than inequities (differences in use which do not reflect differences in need). Further, studies of palliative care use have typically been based on administrative data or retrospective reports of bereaved relatives. As a result, they are limited in the reliability and

comprehensiveness of data they may draw upon to define and assess need for care.

Sen distinguishes between external and internal observations in assessments of equity.²⁷⁷ External observations are those derived from ‘observation-oriented’ subjects such as economics, and typically take a quantitative approach to measurement. Internal approaches come from ‘perception-oriented’ subjects such as anthropology, and often draw upon qualitative methods. He argues that we need both perspectives to deepen our understanding of equity. A comprehensive examination of the process by which patients gain access to SPC thus requires a multi-method approach.

Within SPC, as other health care specialties, the context in which decisions about need for and access to care take place is crucial.²⁷⁸ Whilst guidelines and policies may clearly set out the parameters within which SPC services should operate, it is the day-to-day interpretation and implementation, or otherwise, of these which shape the nature of care received.²⁷⁹ Definitions of need – in the eyes and actions of the providers – may be fluid. They may encompass a diversity of criteria, including economic, clinical, social, lifestyle and personal characteristics (including age).²⁸⁰ As such, operational definitions of need for care may be more about the ‘deservingness’ of a patient rather than strict ‘objective’ medical criteria.⁹¹

However, there is currently little research evidence on how providers make decisions about which patients have a need for SPC. In particular, which aspects and levels of a patient’s physical, emotional and social well being, and functional ability, trigger providers to offer care? What are the contextual constraints within which these decisions are made? And how

might patient characteristics, including age, influence use of and quality of care?

This chapter outlines the ethnographic approach I took to explore SPC providers' views about factors that are relevant when determining need for care. It describes the choice of study settings, entry into those settings, and the participant observation and other data collection undertaken. Procedures for recording and analysing data are set out, along with the ethical considerations and concerns which guided the conduct of this phase of work. I present my findings in two separate sections, based on an analysis of different data sources – documentary evidence, and observations of meetings and interviews undertaken. I develop two alternative models of need for SPC, and then move on to place the concept of need within the context of the day-to-day practices and decision-making of SPC providers. Finally, I briefly consider the role of age and other patient characteristics in determining the nature and level of care provided.

5.1 Aims and objectives

The aim of this component of my research was to develop an understanding of providers' conceptualisations of need for SPC.

The objective was to conduct an ethnographic study of SPC providers to explore their concepts of need for, and factors (including age) influencing use of, SPC.

5.2 Investigation and choice of study design

To gain an understanding of how need for SPC is conceived by providers of such services, and how need and other factors may be viewed as determining use, I chose to use an ethnographic approach. The term

'ethnography' may refer both to a particular methodology, and to the end result of that methodology (a written report of the research).²⁸¹ Ethnography as a methodology originates in social anthropological research, with small scale studies of particular cultural groups. However, it offers a powerful approach in health care research, where the observational methods which form a central component of ethnography can be used to explore differences in action and explanation; what people actually do rather than what they say they do.²⁸²

A particular strength of the anthropological approach is its emphasis on exploring the nature of a phenomenon, rather than assuming it is unproblematic or focusing only on exploring beliefs about it.²⁸² In this way, ethnographic approaches are employed to question categories that are used within the study setting, considering what they mean, their content and form, how they originated and how they are used. This makes this approach particularly useful in considering how need for SPC is conceptualised by providers of that care.

Ethnographic approaches draw upon a variety of methods, and may incorporate both qualitative and quantitative data. The defining aspect of any ethnography, however, is its focus on a particular culturally and socially defined context.²⁸³ An ethnography is commonly situated within a naturally occurring group, whether that is a local community, a hospital or a multi-disciplinary team. The second major aspect of ethnography, as mentioned above, is the use of observational techniques to explore the phenomena under study. This is fundamental in gaining insight into the actions and behaviours of individuals and groups, rather than simply the descriptions of these actions and behaviours which might be given.^{284;285}

Observation of the individuals under study within an ethnography is commonly known as participant observation. There is an ongoing debate about the precise nature of participant observation.²⁸⁶ Definitions of participant observation often highlight a range of stances the researcher may adopt, with implications for their involvement in the study setting. For example, an influential taxonomy by Gold suggested that the researcher may be a full participant, participant as observer, observer as participant, or complete observer.²⁸⁷ One determinant of the nature of participant observation undertaken in each study will therefore be the researcher themselves, including whether their background is, for example, clinical or nursing, their metaphysical stance, and their knowledge of or prior involvement in the study setting.

Participant observation is regarded by some as a method, and others as a methodology. Those who argue for its methodological status assert that it can be linked to a number of different epistemological approaches, and so may not be used without reference to metaphysical beliefs.²⁸⁶ It thus becomes an approach to generating knowledge, rather than a particular technique to obtain data. Reflecting the pragmatic philosophy within which this work is situated, in this study I define participant observation as a method. It is one of a range of techniques I use within the ethnographic approach of this phase of work (see below), and is therefore employed as a data collection tool. Thus, I chose participant observation as one approach to considering the construction of the category of need for SPC.

Ethnographic approaches are being used increasingly within health services research as they enable context-specific understanding of behaviour and beliefs around health care delivery. Observation of team meetings has been used previously to gather data on decision-making relating to patient

referrals and care.^{288;289} By considering the context of care and the actual processes which take place, such approaches facilitate understanding of 'real world' health care organisation. This is vital in investigating variations in use of care, as it enables insights into the construction of need for care and how this might impact on use.

5.3 Methods

Ethnographic and theoretical approach taken

To consider the nature of need for SPC from the perspective of providers of that care, I situated my ethnography within such services. I used a focused ethnographic approach, suitable for use where particular research questions are established prior to commencing fieldwork.²⁸¹

Focused ethnographic approaches are characterized by their restriction to specific areas of study within the field; a 'focus on the particular'.²⁹⁰ The restriction of subject to a selected behavioural or belief area of study within a discrete community or organization also means focused ethnographies are frequently time-limited.²⁹¹ They are commonly found in nursing and public health research, where both time constraints and a desire to conduct research to understand and potentially change policy and practice are conducive to smaller-scale, but more tightly focused, ethnographic research.

In such approaches, data collection is inevitably targeted. To explore the question at hand, the researcher may combine selective episodes of participant observation with a limited number of interviews with key informants, alongside the gathering of other sources of information such as documents and visual data. The use of audio-recordings and subsequent

transcripts alongside fieldnotes is often a key feature of focused ethnographies.

Knoblauch contrasted focused ethnographies with ‘conventional’ ethnographies to develop further the distinguishing aspects of this approach [Table 5.1].²⁹⁰

Table 5.1 Ethnographic approaches	
Conventional ethnography	Focused ethnography
Long-term field visits	Short-term field visits
Experientially intensive	Data/analysis intensity
Time extensity	Time intensity
Writing	Recording
Open	Focused
Participant role	Field-observer role
Notes	Notes and transcripts

In this focused ethnography, I combined participant observation of SPC team meetings with formal and informal interviews and documentary analysis. I worked primarily within one SPC provider, expanding my data collection to two other providers to interrogate the concepts emerging from initial analyses. Taking one ‘index’ site and two ‘satellite’ sites enabled me to gather in-depth data at the first and more targeted data at the others, as is suited to a focused ethnographic method.

My previous experience of SPC was as a researcher, including conducting a number of palliative care studies within the area in which this ethnography was situated. I have no clinical or nursing background, and no personal experience of palliative care provision as a result of illnesses of family or friends. My understanding of the nature of palliative care prior to this piece of research was thus through reading, and through previous conversations and interviews with providers of care. I had not been on a hospice ward, or

seen first-hand the ways in which SPC teams worked. The experience of observing providers of care was thus completely new. This meant I entered the field with few ideas about how things worked within SPC. However, it also meant I had a steep learning curve to be able to 'keep up with' technical discussions I observed. I say more about my experience of conducting the research, and my potential impact on the data, later in this chapter.

My ethnography was framed by the pragmatic philosophy which guided the entire research project. This requires qualitative inquiry to situate itself as far as possible within the empirical natural world, a task to which ethnography is particularly well suited.²⁹² Further, it highlights the importance of considering the interaction between agency and the environment; that is, between individuals (with all their motivations and aspirations) and the context in which they may express their agency.²⁹² Thus, an appreciation of the multiple levels at which concepts of need may be shaped and applied is essential.

In considering the nature of need for SPC, I drew on the most common theory of need within public health, that of capacity to benefit from healthcare.²⁴ I thus approached my observation of staff meetings and other documentary sources with a framework already in place. I was aiming to operationalise this concept by considering *which* dimensions of a patient's situation or the SPC service might relate to a capacity to benefit. Of course, it was possible that I might encounter sufficient challenges to this account to be forced to re-consider its relevance to SPC need, and I thus aimed to maintain a flexible outlook during the process of data collection and analysis.

My focused ethnography was concerned with investigating provider-defined need. It is these views that dictate whether a patient, once referred, is offered

SPC services. It therefore presents a narrow view of need, excluding patients, carers and referrers' conceptualisations. However, it offers the most constructive approach for phase two of the study, where patients were assigned a level of need for SPC. By developing an idea of provider-defined need I applied, as far as possible, the same criteria to categorising patients as those aspired to by these specialists.

In addition, I considered need for SPC for all, rather than specifically lung cancer, patients. Firstly, early discussions with SPC providers determined that the components of need for care were unlikely to vary according to diagnosis, although of course the level of these components might be dependent on the nature of the disease at hand. Therefore, a specific focus on lung cancer was unlikely to generate different definitions of need. Secondly, practical difficulties would render such an approach challenging, as only a small proportion of discussions within SPC providers' meetings would relate to lung cancer patients. Therefore, this ethnography focuses on need for SPC as a whole, although the findings were applied to the later cross-sectional survey of lung cancer patients.

A potential conflict arises between the requirement for 'a definition' of need to conduct a statistical analysis of use, and ethnographic data which may lead me to conclude definitions of need are lacking, unclear, contradictory, or ignored in practice. As discussed in chapter three, in mixed methods approaches such tensions require, as far as possible, prior consideration and exploration. The persistence of irreconcilable contradictions between findings derived from the use of different methods within a study may require the original assumptions to be revisited.

It was partly to address this issue that I drew on a variety of data sources within the ethnography to explore the phenomenon of need. These included documents used by service providers to set out the parameters of their services. I was interested in the feasibility of using these in part to derive a 'public' view of need. I wished to compare this with ideas of need apparent in working practices, using observational data to explore conceptualizations of this phenomenon in day-to-day life. A further aspect I wished to consider was the concept of need used to assess and accept referrals to SPC (perhaps reflected in service documents), and whether and how this varied from need in patients receiving ongoing care. This would also involve a focus on why and when patients may be discharged from SPC – one aspect of how providers may define a lack of need for care. I hoped to use these varying perspectives in developing a measure of need for the cross-sectional survey, reflecting how I felt SPC providers assessed need in patients referred to their care. I accepted, however, that this definition of need may not reflect conceptualisations of need for SPC throughout the entire patient and provider journey.

Prior to the commencement of the study, I therefore expected to be able to derive a workable definition of need for quantitative measurement, but to subsequently consider the influence or otherwise of this concept in providers' work, and the implications this may have for the equitable provision of care.

Situating the study: participating SPC services

Sampling and recruitment of sites

It was essential to sample a diverse range of SPC providers to investigate conceptualisations of need for SPC, as these might vary between settings. I

chose two key characteristics as factors which may influence approaches to the provision of SPC, and which therefore needed to be central to the sampling strategy.

Firstly, SPC providers may be based within the voluntary sector or the NHS. As a result of their different funding sources and management or governing arrangements, NHS and voluntary providers may vary in their conceptualisations of SPC. Voluntary sector SPC providers, whilst in part funded by local NHS sources (typically one third to one half of their income), raise the rest of their running costs from charitable donations and other sources. As stand-alone organisations dedicated to the provision of SPC, this could mean they offer additional services and have a wider definition of SPC. By contrast, NHS services may have more limited budgets and be working within other, larger health care providers which place constraints on the nature of the care they provide.

Secondly, the nature of SPC provision and the patients receiving care will vary whether it is provided in an inpatient or community setting. Inpatient hospice patients are usually admitted for symptom control, respite or terminal care, and have already been under the care of community SPC teams. In an inpatient hospital setting, patients referred for SPC input may or may not have already received community SPC care. In the community, patients referred to receive SPC from a home care team for the first time will not have received SPC previously, although they may have received generalist palliative care. These varying patient characteristics may lead to differing questions on need for SPC input by setting, as summarised below:

- a. Community SPC – does the patient have a need for specialist, rather than generalist, palliative care?

- b. Hospice inpatient care – does the patient have a need for inpatient SPC, requiring intervention, treatment or care which cannot be delivered by the community SPC care and/or in the home setting?
- c. Hospital inpatient care – does the patient have a need for specialist, rather than generalist, palliative care and/or does the patient have a need for inpatient SPC at this time?

Potential research sites were therefore chosen to ensure I included both voluntary and NHS sector providers, and providers offering care in inpatient hospice, inpatient hospital and community settings.

Three providers of SPC were initially selected as potential research sites, based on the sampling strategy. These were:

1. A large, voluntary sector provider offering inpatient hospice and community care, as well as day care
2. An NHS team offering community care, based within one of the cancer network's cancer centre hospitals
3. An NHS team offering inpatient hospital care, based within one of the cancer network's cancer units

The intention was to cover both voluntary sector inpatient and community care through site one, and NHS sector inpatient and community care through sites two and three. However, following initial contact to discuss the research project the medical director of the NHS inpatient hospital team felt that, as they were currently experiencing staffing difficulties, it was not appropriate to take part in a research project at this time. The selected NHS community team then suggested I could attend team meetings of a hospital team they were linked with, who were agreeable to participating in the

project. A full description of the sites who therefore agreed to participate is given below.

Details of sites

The three sites taking part in this phase of work were [Figure 5.1]:

1. Research site one (RS1): a voluntary sector SPC provider with an inpatient hospice, day care unit and community care teams
2. Research site two (RS2): an NHS community SPC team, operating out of an NHS acute Trust.
3. Research site three (RS3): an NHS inpatient hospital SPC team, based at a different hospital site but with organisational links to RS2.

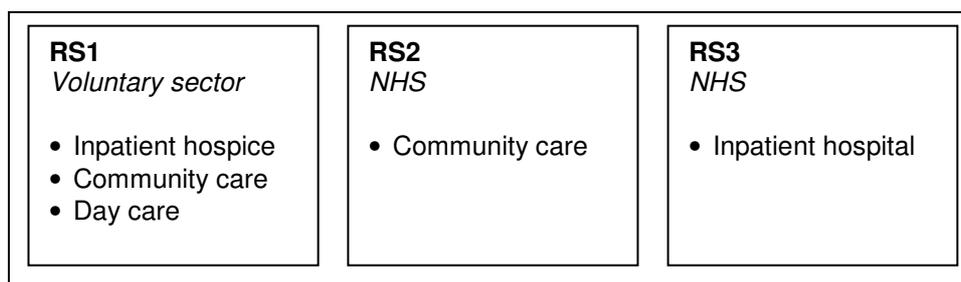


Figure 5.1 Participating research sites

Research site one (RS1)

RS1 is a voluntary sector hospice which offers inpatient, day and home care. They serve a catchment area of around 1.5 million people and care for around 2,000 people each year. Currently, the NHS funds 40% of their running costs; the remainder is generated through fundraising, legacies, voluntary donations and commercial activities.

Inpatient care offers 48 beds spread across four wards, served by a dedicated inpatient nursing staff. Home care is provided by five home care teams, divided according to the geographical area they cover, with dedicated Clinical Nurse Specialists (CNSs) forming the core of each team. Home care is available 24/7, with on-call nurses covering the out-of-hours period. Medical staff work across both inpatient and home care, although only make home visits to patients on request of the nursing staff.

All services are provided according to the hospice Admissions Policy. This states that:

Patients are admitted into the service with advanced cancer, motor neurone disease, HIV or any other advanced, progressive and life limiting non-malignant disease. The complexity of the illness needs the services of a specialist team to achieve control of symptoms and to offer social, psychological and spiritual support to the patient and family. All referrals are prioritised based on reviewing the complexity of problems presented.

RS1 was used as my 'index' site to generate core data on concepts of need and applications of these concepts to patients. It was chosen as the primary site due to it being a particularly rich source of data, with access to inpatient hospice and community care teams within the same organizational entity. I therefore focused my data collection on this site, spending the most time within the organisation. I used data from sites two and three to explore similarities and differences with themes from site one which may arise as a result of differing contexts (organizational, financial, and ideological).

Research site two (RS2)

RS2 is an NHS-funded community palliative care team based at one hospital site within a two-hospital NHS Trust. Together with their counterpart

community team at the other hospital, they serve a catchment area across parts of three boroughs.

They provide a nurse-led home visiting service between Monday and Friday from 9am to 5pm. Out-of-hours advice for patients under their care is available via telephone from 5pm to 11pm on weekdays and from 9am to 11pm at weekends. Medical staff work across the community team and their linked hospital team, although nursing staff are dedicated home care providers. Care is provided according to their criteria for referral, as below:

Most patients will have an advanced, progressive disease, where the focus of care will have changed from curative to palliative and the prognosis is limited. Some patients, who have complex specialist needs, can be referred at an earlier stage, from diagnosis onwards. Patients may be discharged if their condition stabilises.

A demonstrable need for SPC services must be established. Appropriate reasons for referral may include potential / existing difficulties with the following:

- Pain and Symptom management*
- Meeting the psycho-social needs of the patient & their family, and/or significant others*
- Terminal Care/Dying*

Research site three (RS3)

RS3 is an NHS-funded hospital palliative care team based within the same NHS Trust as, but at an alternative hospital to, RS2. They provide advice for inpatients and outpatients at the 900-bed hospital, with a weekly consultant ward round and outpatient clinic appointments. The criteria for referral to the service are the same as for RS2, and referred patients are scored on a 1 to 4 scale for dependency by the CNSs as follows:

1. Professional colleagues contact palliative care team for advice or information. No direct patient contact is made.

2. Palliative care team member makes a single assessment visit at request of referrer. Referrer may or may not be present. No further intervention by the palliative care team thought appropriate. The patient may be re-referred at any time.
3. Palliative care team undertakes a short-term intervention with a review date, when the benefits of continuing palliative care intervention is considered. Further referrals may be needed.
4. Complex physical or psychological or social issues requiring intensive review and continuing assessment from the palliative care team.

The three research sites thus present a broad range of SPC practice and caseloads across both voluntary and NHS sector providers.

The process of negotiating entry into research sites began with my initial approach and meetings about the proposed work. This was facilitated by my prior acquaintance with key medical staff at the voluntary sector provider and the NHS hospital team, who I had met during the course of previous research work. I was therefore already known by some members of staff for my work within the area of palliative care, and this facilitated the arrangement of meetings to discuss the proposed project.

To gain agreement to participate, at RS1 I met separately with the medical director, nursing management, and senior nursing staff. I then attended a research committee meeting, and two staff research meetings, to present the project to the wider medical and nursing staff. Following the granting of approval for the project to proceed, I organised a further round of meetings to discuss how best to introduce the project to staff and gain their consent to take part in the research. As I was proposing to observe all home care team meetings and inpatient admission meetings, information sheets and consent

forms were circulated, through managers, to all medical staff, home care nursing staff, social work and relevant administrative staff.

As the work involved my attendance at a large number of admissions and home care team meetings, I was offered a base in the medical office, where the medical team secretary and the junior medical staff were located. Once I had received full approval to go ahead with the research, I therefore attended the site on a daily basis; in the first week this enabled me to collect consent forms and finalise arrangements before commencing data collection and attending admissions and home care team meetings.

At RS2 and RS3, entry into the research sites required attendance at a team meeting of both the hospital and community team to introduce the project and explain what would be involved. Information sheets and consent forms were distributed directly to staff at these meetings and received back via post. Once research governance approval had been gained, and an honorary contract issued, I attended the weekly team meetings to collect data. Contact with providers was therefore at much more of a distance than at RS1, where I was treated as a new member of staff and spent my working hours mainly on site.

Data collection

From June to August 2005, I spent a continuous period of eight weeks based at RS1. Data collection and analysis were conducted simultaneously, with further analysis ongoing following my disengagement from the research site. I then attended meetings at RS2 and RS3 from January to March 2006, but was not based full-time at these sites as I had been at RS1.

The primary focus of data collection was multi-disciplinary meetings held at the three participating providers to discuss patient referrals, care, discharges and deaths. At RS1 I also conducted both formal and informal interviews. For contextual information on the service I participated in the daily life of the doctor's office, including attending ward rounds and ward meetings on occasion. Finally, at all sites I collected relevant policy documents and operational procedures for documentary analysis. Full details are given below; appendix II (page 387) contains all relevant study documentation.

Observation of meetings

At RS1, I observed 15 inpatient admissions and 12 home care team meetings.

RS1 inpatient admissions meetings.

Admissions meetings take place at 10am every day from Monday to Friday. Their role is to consider the referrals for inpatient admission that have been made to the hospice, to accept or refuse these referrals and, for those referrals which have been accepted, to prioritise these in relation to the availability of beds.

There are usually two participants in the admissions meeting, one a representative from the admissions office (either the admissions officer or the assistant admissions officer), and one a representative from the senior nursing staff (either the inpatient matron, the nurse consultant or, on occasion, the director of nursing). This arrangement had only commenced shortly before the start of my study. Previously, the admissions meeting was attended by the admissions officer, the matron, a consultant physician, a representative from homecare (usually one of the home care team nurse managers) and a social worker.

Occasionally, the admissions' meeting is attended by extra personnel.

During my period of observation, these included a student nurse, the finance officer for the hospice, and (at one Friday meeting) a doctor who was on-call over the weekend.

RS1 home care team meetings

These meetings, which take place three times a week for each of the five home care teams working out of the hospice, are used as forums to discuss new patients referred to the community service, to seek advice on issues or concerns surrounding current patients, to conduct formal reviews of current patients, and to decide whether patients should be discharged from the home care service.

Arrangements for home care team meetings vary between teams. All have at least one full multi-disciplinary team meeting a week, attended by the team's consultant in palliative medicine along with Specialist Registrar/s (SPRs), Clinical Nurse Specialists (CNSs) and the team's social worker. Occasionally, other staff members, such as day centre workers, may be invited to the meeting to discuss a particular patient. Meetings are scheduled to last for one hour. All teams meet with their SPR on additional days of the week, to access medical advice on a more frequent basis.

RS2 community team meetings

At RS2, I attended five community team meetings over the course of two months (January to March 2006). These weekly multi-disciplinary home care team meetings comprise the core team (SPC consultant and CNSs), and occasionally members of the extended team (including SPRs, psychotherapists, social workers and others). The meeting is used to discuss all new patients referred to the team during that week and to recap on all

recent deaths and discharges from the service. Additionally, any current patients with urgent needs or concerns requiring input from the team are presented for discussion. Finally, a selection of all current patients are presented for review at each meeting, with the aim of all patients being reviewed at a minimum of every two months.

RS3 hospital team meetings

Multidisciplinary hospital team meetings at RS3 also take place on a weekly basis. I again attended five of these meetings, over the same two month period as RS2. Meetings are attended by the consultant, SPRs, and CNSs and frequently the complementary therapist, psychotherapist, psychologist and pharmacist attached to the team. These meetings are used to discuss all current inpatients seen by the team, as well as all recent deaths and discharges which have occurred.

Recording of meetings

With the written consent of participants, all observed meetings were audio-taped and transcribed to provide a detailed recording of events. I wrote detailed observation notes following each meeting, with a particular focus on how referral information about each patient was discussed by the team; what domains (such as symptoms, psychosocial and functional issues) were covered by the discussions; and on what basis decisions were made to accept or not accept referrals, or to make discharges from the service. This is covered in more detail in the fieldnotes section below.

Formal interviews

I also conducted five interviews with hospice staff members at RS1, three with senior nurses and two with doctors. To guide the conduct of each interview, I developed an interview guide sheet [see appendix II, page 393].

This set out the major topics of interest I wished to cover, with a list of prompts to facilitate exploration of each area. It did not include specifically worded questions. I opened each interview by asking about the participant's role within the SPC service, to provide contextual information. I then moved on to ask about their broad views on definitions of palliative care and ideas of need for healthcare. The main body of the interview covered their views on accepting referrals to inpatient and home care services, reasons for rejecting referrals or discharging patients, the perceived benefit of SPC to patients, and how these benefits may vary between patients (including whether patient age was related to benefit). Finally, I focused on specific dimensions of need for SPC. All interviews were audio-taped, with written consent, and transcribed in full.

Informal interviews

During my time at RS1, I conducted a number of informal interviews and conversations with doctors, nurses and administrative staff including the two admissions officers. These were used to clarify points of procedure, raise queries about issues arising, and explore individual's views on need for services, benefit from services, and patient characteristics on an ad-hoc basis. These conversations were recorded in my fieldnotes. Consent for the conduct and use of these interviews was negotiated with each participating individual, all of whom had read the information sheet and signed a consent form for participation in the study.

Documentary sources

The final source of data was documentary. For RS1, these documents included the admissions and discharge policies, which covered all services offered (inpatient, home and day care); the operational policy for the home care teams; the inpatient admissions scoring sheet and its accompanying

guidance; and a blank patient notes file. For RS2 and RS3, which are governed by a common administrative structure, I obtained the joint operational policy (covering all aspects of the running of the services including referrals and discharges). I also acquired additional documentation covering the entire Palliative and Supportive Care Network, including the referral pathway and referral form.

In addition to documentation from the participating sites, I also gathered a small amount of textual evidence from other SPC providers in England to provide a broader perspective on SPC work. To achieve this, I sampled one SPC provider from each of the nine regions in England covered by the 'Hospice Information' directory. As I did not have ethical or research governance approval to gain confidential documents directly from providers, I was limited to publicly available information. I therefore visited the website for each sampled provider and downloaded or copied all text relating to their definitions of SPC, who they offered these services to, and their referral procedures. I also requested any further information they made available to members of the public on their services and operational procedures. All documents were converted into electronic form, as necessary, for analysis along with all other data [Table 5.2].

Table 5.2 Documents analysed from additional services		
SPC provider	Services provided	Documents analysed
A	Inpatient beds Home care Day care	Website
B	Inpatient beds Home care Day care	Website Referral form and guidelines
C	Inpatient beds Day care	Website Eligibility criteria Referral form
D	Inpatient beds Home care Day care	Website Referral form and guidelines
E	Inpatient beds Day care	Website
F	Inpatient beds Day care	Website
G	Inpatient beds	Website Referral form and guidelines
H	Inpatient beds Home care Day care	Website Referral form and guidelines
I	Inpatient beds Home care Day care	Website Referral form and guidelines

Fieldnotes

Fieldnotes were a key element of data collection. I did not write notes whilst observing meetings for two reasons. Firstly, a number of the meetings I attended were small, with only two participants, and I felt that to write notes would have re-emphasised the observation, potentially inhibiting the natural flow and the content of the meeting. Secondly, all meetings were audio-taped and fully transcribed, so the verbal content, as well as other events such as the coming and going of participants, phone calls and so on, was recorded. However, fieldnotes were made immediately following each meeting and interview, as described below.

Fieldnotes were created in three stages following Lofland's and Lofland's approach.²⁹³ Mental notes were a way of focusing my observation whilst in a

meeting, considering questions such as who was in attendance and their participation in the meeting, the procedure followed, and key discussions which related to ideas of need. Such notes were thoughts, not recorded at the time, and were an attempt to 'make sense' of each situation I observed with reference to my major topics of interest. Mental notes were converted into jottings immediately after the meeting ended. Jottings were made directly in my notebook whilst in an inconspicuous place. At RS1 this was usually back at my desk in the medical office; at RS2 and RS3 this was on the way back to my office following an observation session. At this stage, I considered key words, quotes and points of discussion. Jottings also often contained rough sketches of the meeting room layout and participant location. At RS1 admissions meetings, I also included in my jottings the contents of the admissions board at the beginning and at the end of each meeting, so I had an accurate record of the decisions that had been taken.

I converted mental notes and jottings into full fieldnotes, which were my interpretation of everything that had taken place in that meeting and in me as I observed the meeting. Full fieldnotes were written up the same day of observation, directly into a computer file, with a separate file for each day (RS1) or meeting attended (RS2 and RS3). In these notes, I focused on key decisions which had been taken, particular phrases which had been used, and cases and concepts discussed. I also included emerging analytic ideas, and my own feelings. They therefore represent the full record of observation, and were treated as data and included within my analysis. I used a fieldnote notation system to distinguish between different sources of text [Table 5.3].

Table 5.3 Fieldnote notation system	
Exact recall of quotations	“quotations”
Less certain recall of quotations or paraphrasing	‘apostrophes’
Verbal material but no quotation / general observation	no markings
Analytic ideas and inferences	(brackets)
Emotions and opinions	[square brackets]

Transcription

All audio tapes of meetings attended were transcribed in full. I undertook the transcription of seven meetings myself; the remaining thirty meetings were transcribed by two professional transcribers, who were briefed on the confidential and sensitive nature of the data. Transcription commenced at the same time as data collection, to enable ongoing analysis, although owing to time constraints not all meetings were transcribed until after data collection had ceased. To ensure standardised and accurate transcription, the transcribers were given a detailed summary of the organisation and personnel of the three research sites, a full list of commonly used drugs in palliative care, a list of commonly used medical abbreviations (e.g. b.d. [bis die, twice daily]), guidance to commonly used terms (e.g. ‘mets’ to indicate cancer metastases), and the transcription conventions and format I wanted to be used. I did not require detailed transcription markings of pauses in speech and other aspects of discussions; I did however require inaudible speech and stage directions (e.g. [laughter]) to be recorded.

The process of data collection

The process of data collection at RS1 involved my immersion within the staff environment. For two months, I was based in the doctor’s office on site. I was given an honorary contract and went through the human resources procedures necessary for this, including being issued with a staff handbook and identity card. Yet I was not a new member of staff, I was an external

researcher there to observe procedures and events. I felt drawn in as though I was starting a new job, and an urge to 'fit in' and build relationships. However, I was also acutely aware that I had no skills or knowledge relevant to this world, and that I wished to try and learn how things worked without losing my analytical stance. After several weeks of data collection, I took a short break, and it is interesting to look back and see the following in my fieldnotes:

As I left the building, I felt quite sad that I wouldn't be back for a while – it would be so easy to slip into that world for months at a time and probably quickly lose focus on the job in hand [...] it has definitely made me conscious of how attached I have got to RS1 and the characters in it and the set routine by which every day is run.
Fieldnotes RS1 5 August 2005

Immersion in the world of SPC provision also opened me up to the emotional consequences of hearing distressing details of patients' condition and care. Listening to stories of pain, debilitation and emotional trauma was hard. At times this had a particularly strong impact on me as I felt frustrated I was not qualified or able to directly support any of these people. It sometimes made me feel inadequate, too; what was I achieving as an observer compared to those who were involved in providing care? My feelings certainly had an impact on me during my time at RS1:

When I was walking out of the hospice today, I felt a rush of emotion that I just had to get out of the place. I was walking down the corridor away from the doctor's office and got a surge of overwhelming feeling that it was all about death and dying and I had had enough. [...] it is hardly like I am working directly with patients and carers - although I am listening, day in and day out, to all these terrible stories about faceless patients and their dreadful symptoms. I also felt that the hospice is slightly set apart from reality, existing blissfully in its own little world - no wonder [my colleague at work, a SPC registrar] once said to me she would never want to have a full-time consultant post at a hospice.
Fieldnotes RS1 22 July 2005

By contrast, my role at RS2 and RS3 felt very different. I primarily attended meetings of the teams, with little interaction outside of these times. I therefore maintained much more the role of observer, and my relationship with staff consequently stayed relatively distant.

Inevitably, however, my presence had an impact on all those who participated in the study at each site. Whilst I tried to stress prior to attending meetings that staff should just carry on as usual, my first appearance usually invoked something similar to the following:

Very aware of my presence and the microphone at first in this meeting – with the specialist registrar and one CNS both separately asking ‘is it on?’ about the microphone when they came into the room. The consultant also repeatedly referred to the microphone – joking that the CNSs hadn’t brought any patients because I was coming (it was a very quiet meeting). I noticed one CNS trying to pour coffee miles from the table so the microphone didn’t pick it up, and she also removed the box of tissues from the table so as not to make too much noise when pulling one out.

Fieldnotes RS1 21 July 2005

However, following initial self-consciousness, meetings tended to proceed without further reference to me or the microphone. At subsequent meetings, I felt that staff tended to be more relaxed from the outset. It is, of course, impossible to know how conversations may have been altered as a result of my attendance and the recording process. The fact that a substantial part of one meeting was taken up by a discussion of the previous night’s Eastender’s plot suggests that staff became relatively relaxed about how I might be viewing them and their work.

Data analysis

Fieldnotes, full transcripts of meetings and interviews, and documentary evidence were entered into QSR NVivo7 (later NVivo8) software to assist in

analysis of the data. The analytical process is summarized in Figure 5.2, and described in detail below.

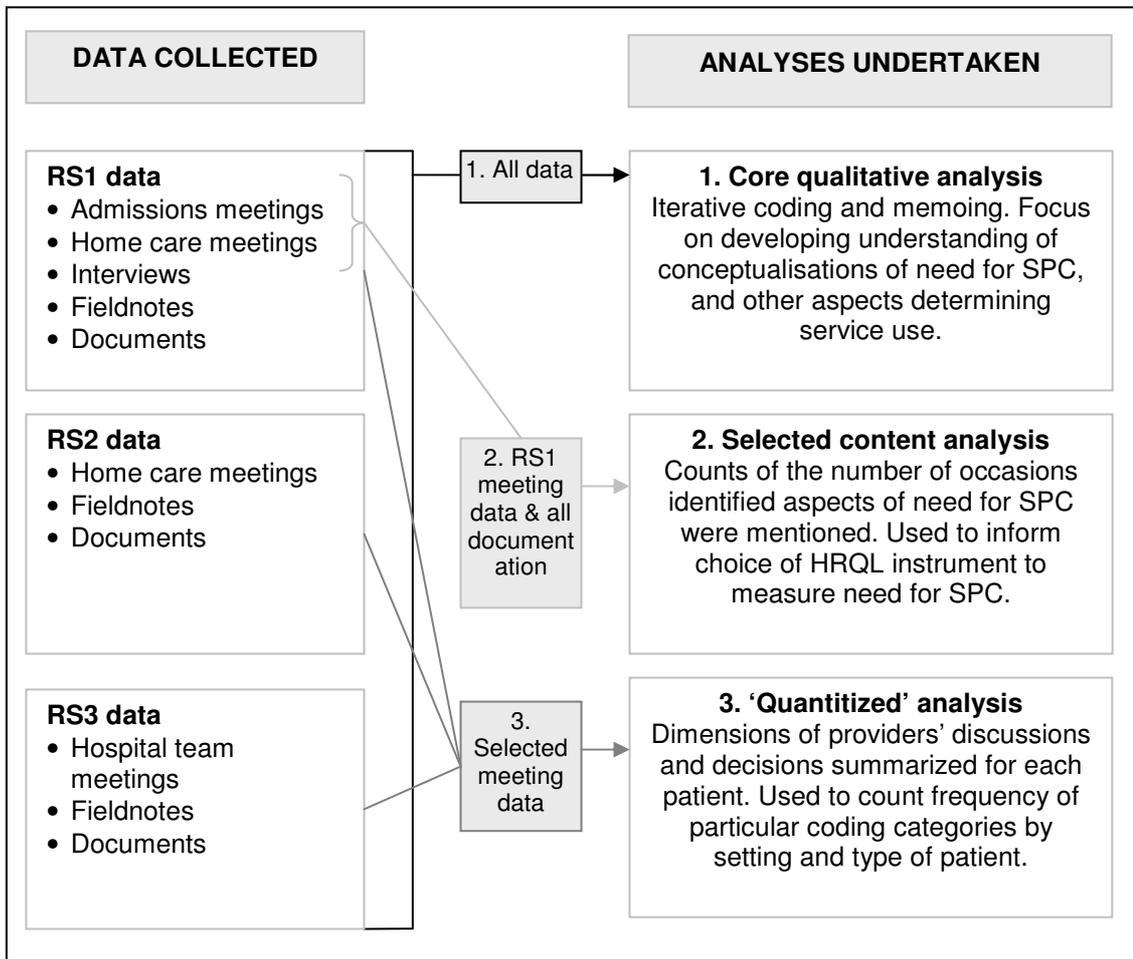


Figure 5.2 Analyses undertaken on data collected

My core qualitative analysis started concurrently with data collection. To guide my analysis I employed a system of coding and memoing developed by Lofland and Lofland.²⁹³ This approach to qualitative data collection and analysis was developed in the USA by generalist, rather than medical, sociologists. Its typological approach to analysis is primarily characterised by an interest in classification and the derivation of categories for the phenomena of interest. It sets out a series of reflexive steps through which data are generated, coded, and re-coded, making particular use at all times of jottings and memos to aid analytical thinking. I chose this approach as it

provides a robust and clear framework for analysis, which I felt was particularly well suited to guiding my thoughts within the focused ethnography.

Firstly, I entered into a process of further familiarization with the transcripts and documents, reading and re-reading these and listening to taped extracts whilst considering ideas I had jotted down in the course of being at the research sites. In this initial stage I outlined some rough ideas about concepts of need and their role within SPC work. Pertinent excerpts within transcripts that illustrated these ideas were highlighted and assigned a code. At this stage coding was prolific, with new codes being used freely to highlight a wide range of potentially relevant elements. Codes initially remained in a long list rather than being grouped or placed into a 'tree' system. As I coded, I used memos to summarise and synthesise my work. These memos, from brief jottings to several pages of detailed musings, were created for each new code I assigned, as well as for potential overall themes or groupings of codes. I also used memos to record the process of analysis and my thoughts on this process.

After the initial coding had been conducted across all data, I moved to a more focused period of iterative coding. Within this stage of the analysis, I rearranged, collapsed and sorted codes as I revisited the data and the literature and considered my direction of thinking. Themes were cross-checked both within and between data sources to test and improve the validity of my emerging thoughts. Coding groups were developed, old codes deleted and new ones added. I began to pay more attention to questioning different emerging concepts of need based on the differing types of data I had collected. However, such questioning also led to confusion as a result of attempting to juggle the different contexts and dimensions within the data

(inpatient versus community settings, new versus current patients, documentary versus observational data). Eventually, this led to the decision to temporarily set aside the analysis and consider how else I could interrogate my data to develop a cohesive analytic framework.

Whilst the initial analysis was ongoing, I was also looking ahead to the next planned phase of the study, the cross-sectional survey of use of SPC by lung cancer patients. This required a measure of need of SPC. Full details of the choice of this measure are given in the next chapter; however, the analysis of data which guided this choice is discussed here. As already mentioned, I was aware that the derivation of dimensions of need for SPC to choose a measure of those dimensions may be complex in the light of other concepts thrown up by my observations and analysis. In my survey of use, I wished to employ a measure of need used by providers in assessing patients referred to their services. To achieve this, I conducted a content analysis, initially drawing on documentary evidence including admissions and discharge criteria and patient assessment tools to develop a coding framework. I then applied this to transcripts of inpatient admissions and home care meetings at RS1. Data collection at RS2 and RS3 was only just commencing at this stage.

Content analysis as a term is currently used to describe a variety of approaches, from quantitative analysis of qualitative text to in-depth qualitative data analysis.²⁹⁴ However, the original approach of content analysis was to investigate the existence and the frequency of ideas of interest (particularly words or phrases) within the data at hand.²⁹⁵ 'Qualitative content analysis', as it is sometimes known, therefore involves coding data using inductively and/or deductively derived codes, and counting the occurrence of these codes within the data.^{296;297} It is a particularly powerful approach in assessing the nature and relative

importance of terms or concepts within the phenomena of interest, such as the components which may comprise concepts of need for SPC.

Drawing on initial coding lists, a framework for potential aspects of need for SPC was compiled. This focused particularly on dimensions of importance highlighted by prioritization scoring systems and assessment tools, as well as elements discussed by staff when presenting or assessing new patients. This differed from the models presented later in this chapter by its detailed focus on specific concerns or complaints which were measured and addressed by SPC providers. The framework was then applied to RS1 transcripts to generate counts of the number of occasions on which these terms or concepts were used. The findings from this content analysis were used to help determine the choice of HRQL instrument to act as a measure of need for SPC, as described in full in Chapter 6.

The conduct of a content analysis to inform the cross-sectional survey design subsequently inspired me to revisit my primary qualitative analysis using a different approach. Following the completion of all data collection, I therefore conducted an additional, adapted content analysis across the entire data set. I hoped that the re-arrangement and interrogation of the data using a quantitative perspective might help to resolve the disarray I felt my current codes and memos were in. This 'quantitizing' of qualitative data to conduct a secondary analysis is common within mixed methods studies, particularly where the frequency or intensity of observed phenomena is an important aspect of gaining understanding of events.²⁹⁸ I wanted to use this approach to understand the distribution of potential dimensions of 'need' within discussions about each individual patient, and the nature and frequency of decisions that were taken in each case. I hoped that by considering the frequency and distribution of particular coding categories I would drive

forward further understanding on my return to the main qualitative analysis.

To achieve this, I created Excel charts with column headings based on key coding categories I had employed within my qualitative analysis. For each meeting transcript, I read through the text, creating a row in the spreadsheet for each patient who was discussed, and noting whether these patients were recently deceased, new to the service or current. For hospital team meetings patients who had been discharged from hospital care were also included. I excluded hospice inpatient admission meetings from this process as I wished to focus on potential aspects of need for SPC – rather than a need for hospice care by patients already receiving community or hospital palliative care.

The dimensions of discussion for each patient were then summarized within the relevant column headings. At the end of this process, I had Excel charts for all home care and hospital team meetings detailing every patient discussed, the nature of these discussions, and any decisions that had been taken about the patient's care. From these charts, I went on to produce summary graphics counting the frequency of discussion about particular dimensions of care, and decisions taken, according to the type of patient. In this way, I gained a different understanding of the nature and purpose of the observed meetings, and the emphasis participants placed on particular aspects of SPC.

I thus returned to my primary qualitative analysis with new ideas for considering and interrogating the data. This energized a final phase of coding and memoing, in which codes were refined and arranged into hierarchical groups. I also began to present codes and code groupings in the form of models and diagrams to illustrate aspects of need, and the role of

provider practices and social relations on these aspects. I also considered how patient characteristics, such as age, influenced the process of care. I paid particular attention to any contrasts between documentary and observational data. The process of analysis was further refined as I began to piece together the memos into larger documents and explanations of my findings.

Data confidentiality and storage

A number of steps were taken to ensure that data was stored securely, and that confidentiality was respected. All participants were allocated a pseudonym where appropriate, and only this was attached to transcripts from the audio tape recordings of interviews, and used in fieldnotes. All patient and carer initials used in the data extracts presented in this chapter are replacements for their actual initials. Tape recordings were listened to only by me and members of the immediate supervisory team, and by the transcribers. The transcribers signed a confidentiality agreement prior to commencing transcription. Following transcription, audio tapes were stored in a locked filing cabinet, and transcripts were kept on a password protected computer.

Ethical considerations and concerns

The conduct of ethnographic research raises a number of unique ethical considerations. Of overriding concern is the issue of informed consent for those who will become involved in the research project through their presence in the environment which the researcher is observing. This focused ethnography took as its key data source multidisciplinary meetings within the participating research sites. It was therefore essential to gain consent from all meeting participants, ensuring they had received full information about the study, and had been able to consider their participation and ask questions before agreeing to my presence in meetings. In preparation for the

project, this issue was discussed with key staff at participating sites, and it was agreed that the researcher would take particular steps to stress to all potential participants the voluntary nature of taking part in the project. If a staff member objected, I would not attend the meetings at which they were present. In the event, this situation did not arise, and written consent was obtained from all known participants, including medical and nursing staff, social workers, administrative and other staff.

Yet, in observational research, it is inevitably challenging to anticipate all ethical dilemmas which may arise within the field.²⁹⁹ Consent is an ongoing process, rather than a simple signature on a consent form, and may need to be re-negotiated and adapted as the project develops and new situations arise unexpectedly.³⁰⁰ It may also not always be possible to gain consent in advance. In my study, despite efforts to reach every staff member who was likely to attend meetings, I encountered a number of situations which gave rise to potential ethical difficulties. I give three examples here to illustrate some of the issues which arose.

Firstly, mid-way through a home care team meeting I was observing and recording, an invited individual (from an outside organisation) arrived to join a particular discussion about a current patient. I was not aware this was to happen prior to the meeting commencing. The individual came into the meeting and immediately joined in the discussion; I was not introduced or acknowledged, yet the tape recorder was running. Should I interrupt the discussion to introduce myself and the study? Should I stop the tape recorder? In the event, I did not feel it was appropriate to interrupt the ongoing clinical discussion; nor did I wish to stop the tape recorder (which was in the middle of the table a long way away from my sitting position), as I felt this would inevitably also act as an interruption. I resolved to discuss

the study with the individual after the meeting and to explore their views about participating, although I was anxious that such 'retrospective consent' was ethically difficult. In the event, the individual left prior to the end of the meeting. On reflection, I decided to excise the discussion which involved that individual from the subsequent transcript, and therefore exclude them from the study.

On another occasion, I turned up to attend an inpatient admission meeting to find it was to include a student nurse on placement at the study site. I did not have any information sheets or consent forms about the study on my person. However, I did have the opportunity prior to the commencement of the meeting to introduce myself, the nature of the project, and gain a verbal agreement that the individual was happy to be recorded for the purposes of the study.

Finally, a wider issue arose about the use of information gained outside of the meetings which were the primary focus of the research. Particularly during the time I spent at RS1, where I was based within the junior doctor and medical administration office, I was exposed to a large number of discussions of which I was not part, but which were on occasion relevant to my research. Consent had been obtained from all the present members of staff for me to observe the meetings which they attended, and to interview them if requested. I had not, however, obtained consent to conduct a wider observational study of the day-to-day activities within the service. I resolved that, without returning to the ethics committee which had approved the research, and re-negotiating consent with all staff members, it would be unethical to note or use such overheard conversations. That much was clear, although it is of course difficult to 'forget' things which I had overheard which shed light on the subject at hand. Aware of this dilemma, and with an

increasing need to clarify or expand upon issues noted within meetings, I resolved to negotiate consent for 'informal' discussions/interviews with key members of staff. I therefore approached a number of individuals to ask if they were happy to discuss arising issues with me, and to have their comments incorporated within my fieldnotes. All those approached in this way were happy to cooperate, and most expressed surprise at my concern about what data I could or could not ethically use. From their perspective, they were aware that my overall aim was to investigate concepts of need for care, and knowing that I was conducting observational research they expected me to use multiple sources of data to this end, including my informal chats with them and my observations of the day-to-day running of the service.

This situation in particular highlighted the challenges of following the consent procedures which are suggested and approved by ethics committees. Despite best efforts to clearly summarise the planned research within information sheets, and on consent forms, it is difficult to anticipate in advance of ethnographic research the course the project will take, and the dilemmas which arise. I would argue that judgment is required on an ongoing basis to determine whether individuals are aware of and freely participating in the research, and that written consent alone, obtained at the commencement of the study, is inadequate. As Hem et al argue, there is no simple solution to the ethical conduct of observational research, and researchers must be flexible yet aware at all times.³⁰¹

A final ethical note is important here, on patient confidentiality. This issue arose in discussions with the approving ethics committee; namely, that by my presence in meetings I was party to information about patients, including their names and details on their medical conditions and social situations,

without their express consent. It was not feasible for me to gain patients' consent, as particularly in the inpatient hospital and hospice meetings referrals could be made right up until the start of the meeting. The ethics committee, on reflection, agreed that the study could go ahead, approving the safeguards I suggested preserving patient confidentiality. No transcripts or fieldnotes contained identifiable patient data such as their name or area of residence. Additionally, it was agreed that any other remaining details of data that could potentially allow identification of individuals would be removed prior to placing information from this project in the public domain.

Ethical approval for this phase of work was sought and received from the relevant NHS Local Research Ethics Committee. Research governance approval was sought and received from the participating NHS Trust, and the equivalent from the participating voluntary sector provider. I had an honorary contract with each research site to conduct the research.

5.4 Results

Analysis of documentary data

I first present findings derived from my analysis of documentary data. This is done to provide a clear counterpoint between conceptualisations of SPC derived from policy, and those derived from observations of practice. That is – what does SPC say it does, and what does it actually do? These distinctions became increasingly important throughout the course of my analysis, and presentation of findings in this manner helps clarify the importance of context in concepts of need.

I identified a strong and consistent message about the aim and domains of SPC through my analysis of documents. Documents described 'typical' or

'ideal' patients to receive SPC, and provided details as to how these patients may be prioritised in particular circumstances.

The 'holistic quartet' of needs

All documents examined clearly identified the primary purpose of SPC as improving quality of life:

The aim is to achieve the best quality of life possible.

[Hospice B website]

The goal of enhancing quality of life was further clarified across all services by a focus on what I identified as the 'holistic quartet' of integrated SPC assessment and activity – physical, psychological, social, and spiritual needs. These terms were directly and repeatedly used in numerous documents. For example, RS1's discharge policy states that discharge may occur when:

The patient's physical, social, psychological and spiritual needs have been responded to and do not require ongoing care.

[RS1 Discharge Policy]

A multi-dimensional conceptualisation of patient need, encompassing four key domains of life, is therefore routinely expounded. However, within such documents closer scrutiny revealed that it was common for the primary emphasis of work to be placed on physical symptoms such as pain and breathlessness. So, the operational policy for sites 2 and 3 separates out physical needs from other needs, stating:

SPC needs include potential/existing difficulties with the following:

(a) Pain and symptom management

(b) Meeting the psychological, social and spiritual needs of the patient & their family and/or significant others

(c) Terminal care/dying
[RS2 & 3 Operational Policy]

Other documents repeat the dichotomy of ‘physical symptoms’ versus ‘other needs’. An RS1 form used for requesting transfers for patients from hospital to inpatient hospice care asks referrers to:

Elaborate on reasons for transfer:

(1) Physical

(2) Emotional, psychological and spiritual needs of patient and/or carer

[RS1 hospital transfer form]

The centrality of families and carers

A secondary aspect of the nature of SPC was an emphasis on the assessment and involvement of families and carers. Alongside patient care and then beyond into bereavement support, all services stressed the importance of meeting carers’ needs. It is particularly notable that the RS1 Admissions Policy specifically states that inpatient admission would be allowed for a terminal care patient if a family needs psychological support – even if the patient's symptoms are themselves stable. The inclusion of carers within the SPC approach is summarised succinctly on one hospice’s website:

Palliative care is a term used, where the focus is to meet all the needs of the patient – physical, emotional, spiritual and practical. The aim of care is not to cure but to improve the quality of life, not just for the patient, but for family and close friends.
[Hospice N website]

The ‘ideal’ patient

Suitable patients for the receipt of SPC were described as those with life-limiting diseases which are no longer responsive to curative treatment. For example, RS2 and RS3’s operational policy specified patients would usually

have 'advanced incurable progressive' disease; this focus on progressive and advanced illnesses was echoed in several other referral policies. Patient age or other characteristics were not mentioned as relevant in determining need for care in any documentation. Cancer was the key diagnosis for patients, with some services stating clearly that this was their main area of expertise. Other services either identified alternative eligible non-cancer diagnoses by name, or grouped them together to state 'cancer and other' patients would benefit from their services. RS1 states in its admissions policy:

Patients are admitted into the service with advanced cancer, motor neurone disease, HIV or any other advanced, progressive and life limiting non-malignant disease.
[RS1 Admissions Policy]

There was less clarity on the stage of disease patients may be at when referrals to SPC were judged to be appropriate. Many services, including all three research sites, stressed that SPC would support patients at all stages of disease, from diagnosis onwards:

We can provide care and advice from diagnosis to the final stages of a life-threatening illness.
[Hospice D website]

However, RS1 added the caveat that patients at an early stage would have 'uncontrolled symptoms', whilst RS2 and 3 state that:

Some patients, who have complex specialist needs, can be referred at an earlier stage, from diagnosis onwards.
[RS2 and 3 Operational Policy]

Thus, whilst stressing that patients may receive care at any stage of disease, services also wish patients to have 'advanced', 'progressive', 'uncontrolled'

or 'complex' disease. This may well apply to patients who are diagnosed at a late stage of disease – for example, when cancer has metastasised widely – but the majority of patients diagnosed with 'suitable' diseases will not, at such a point, meet these other criteria.

The debate about when in the disease trajectory support should be given is further highlighted in the Operational Policy for RS2 and RS3, which states that one of the criteria for discharge from the service may be that 'investigations reveal less advanced disease than previously thought'. A further criteria for discharge, identified by all three research sites as well as other services included in the documentary analysis, is the stability of the patient's disease. RS1's discharge policy gives the most explicit definition in this situation. Discharge may occur if:

The patient's disease is clinically stable and has remained so for a period two-three months. Given their disease status the patient is not expected to deteriorate in the following three months and the RS1 team no longer has an active role in their care.
[RS1 Discharge Policy]

This returns to the importance of 'progressive' disease in defining suitability for SPC.

Finally, all documents analysed repeatedly highlighted that patients suitable for SPC interventions were those with 'complex' needs, illnesses or symptoms:

The complexity of the illness needs the services of a specialist team to achieve control of symptoms and to offer social, psychological and spiritual support to the patient and family. All referrals are prioritised based on reviewing the complexity of problems presented.
[RS1 Admissions Policy]

However, no documents clarified how such complex needs or symptoms were identified or classified, or how 'complex' was to be defined in this situation. Thus, although complexity is viewed as a key determinant of eligibility or suitability for SPC intervention, this remains an ill-defined and vague concept within policy and procedure.

Patient prioritisation

As SPC providers are likely to receive more referrals than they can care for, some system of prioritisation may be used. In home care services, this may take the form of offering different levels of input (in terms of frequency and length of visits), rather than actually declining to accept referrals to care. However, within the inpatient hospice setting with a finite number of beds, prioritisation must occur when there are too few spaces for the number of referrals received – in this situation, referrals may be declined or deferred.

RS1, and to a lesser extent RS2 and 3, operate formal scoring systems to help prioritise referrals. RS1's scoring system, developed in-house, is used to assess referrals made for inpatient hospice care [Table 5.4]. A score is assigned to each patient by the referring professional. With a possible maximum of 14, the score covers three domains (physical symptoms, emotional/psychological problems [for both patient and carer], and social/practical care issues); it also takes account of the predicted likelihood of dying shortly. Under social/practical care issues, living alone, having children under 18 within the household, and having a current care package which is deemed insufficient will all lead to patients being scored more highly. The inclusion of emotional and spiritual problems for carers emphasises the perceived importance of family and friends in creating a need for inpatient SPC intervention. In this way, the scoring system covers all aspects of the 'holistic quartet' – physical, psychological, social and

spiritual – as well as adding additional urgency for patients who are actively dying. Patient scores are used within the daily admissions meetings.

However, the referral policy stresses that this system is simply to ‘assist with decision making’ and is ‘not an exact science’.

Table 5.4 RS1 Admissions criteria score sheet	
Physical	Score
Severe physical symptoms	3
Moderate physical symptoms	2
Some physical symptoms	1
No physical symptoms	0
Emotional/psychological	
Severe or many emotional/spiritual problems	3 for patient and 3 for carer
Moderate emotional/spiritual problems	2 for patient and 2 for carer
Some emotional/spiritual problems	1 for patient and 1 for carer
No emotional/spiritual problems	0 for patient and 0 for carer
Social/practical care issues	
Lives alone	1
Children involved (under 18 years old)	1
Current response insufficient (details please)	1
Terminal care	
Patient is dying within 48 hours	2
Patient is dying within 2 weeks	1
Total score out of 14	

RS2 and RS3 also operate a prioritisation system, one for hospital patients and one for home care patients [Table 5.5]. This takes a slightly different approach, using broad categories to define the level of input the services will provide to patients, ranging from minimal to frequent contact.

Table 5.5 RS2 and RS3 dependency levels	
Levels of dependency for Hospital Patients	
1	Professional colleagues contact palliative care team for advice or information. No direct patient contact is made.
2	Palliative care team member makes a single assessment visit at request of referrer. Referrer may or may not be present. No further intervention by the palliative care team thought appropriate. The patient may be re-referred at any time.
3	Palliative care team undertakes a short-term intervention with a review date, when the benefits of continuing palliative care intervention is considered. Further referrals may be needed.
4	Complex physical or psychological or social issues requiring intensive review and continuing assessment from the palliative care team.
Levels of dependency for Community Patients	
1	Minimal contact where existing support networks are in situ and patient has stable symptoms, but diagnosis indicates a probable short prognosis.
2	Unstable symptoms requiring regular review from CNS, or where support network not established.
3	Complex symptoms/terminal phase/rapid deterioration, requiring frequent contact by CNS.

In spite of these formal systems for prioritising patients and/or the workload of the SPC teams, few documents referred specifically to how prioritisation decisions should be made; that is, how they would decide if one patient's need for SPC is greater than another's. RS1's admissions policy states, for inpatient care, that;

...occasionally the overall context of the presenting patient, even with a low score, may take priority. The Admissions Team is at liberty to change the score of the referrer.

[RS1 Admissions Policy]

However, it does not state what aspects of the 'overall context' may be considered. Only one document scrutinized offered any further details on the prioritisation of need:

Please note that acceptance of a referral is based and prioritized on clinical risk issues alone. For example, if two patients have been referred to the in-patient unit and only one bed is available, the patients will be prioritized according to clinical need. If one

is at home, alone and in pain, they would take preference over a patient who was in pain but in a hospital bed. In the hospital, the patient is at least safe and looked after.
[Hospice D Referral Policy]

This scenario suggests that 'clinical need' is portrayed as extending to social circumstances rather than physical symptoms alone.

Overall, in spite of clear instructions within documents as to how patients may be scored or their level of required input assessed, no guidance is given as to the process of prioritization which should be undertaken, or on how scores should be actually used. There are therefore no clear criteria within policy and procedural documents to govern decision-making on levels of need.

The documentary analysis presented above provides an insight into the public face of SPC, how its activities are defined and presented for staff, patients, families and a wider audience. The consistency of content between documents suggests a high degree of consensus on the nature of SPC amongst providers. Interviews conducted during the course of this work also supported this model of care. When asked what their idea of SPC was, providers universally presented the 'holistic quartet' concept of care:

Well palliative care is a supportive approach to people who have life-threatening or life-limiting illnesses. And it ought to encompass the, not just the patient and their symptoms and their emotional well-being, but it ought to also cover the family that is close to them. And I think that's a philosophy, if you like, and an approach, that needs to be developed in healthcare generally. SPC I see as being, end of life care, for people who have slightly more complex emotional, social, physical symptoms. I am of the brigade increasingly, that palliative care in a way needs to start at diagnosis, the approach. But SPC needs to be limited to end of life care.

Nurse 1 interview, RS1

Well I think everybody's perceptions about palliative care by now are shaped by the evolving WHO definitions of it. So, it's the care of people who have progressive, life-limiting, incurable disease, that is causing symptoms, maybe physical, but may also be psychological. So they're people for whom death can be anticipated within a foreseeable period.

Doctor 1 interview, RS1

An initial model of need for SPC

These 'public' statements and documents present a clear and consistent conceptualisation of need for SPC, illustrated in the model below [Figure 5.3]. To be referred, patients must have an advanced, progressive illness with complex needs. SPC services will respond to a referral by taking a holistic approach to assessing a patient's, and their carer's, needs across four key domains - the physical, psychological, social and spiritual. Treatment and care from the multi-disciplinary SPC team will continue to focus on this 'holistic quartet' throughout the patient's illness. Discharge will only be considered if a patient's disease and their symptoms are stable, or if the extent of their disease has lessened as a result of a good response to curative treatment.

From this documentary analysis we therefore have a strong concept of need which suggests suitable patients will benefit from SPC in domains other than the physical, and which incorporates the needs of carers and families.

Whether this model, or a different approach, is used in the observed practice of SPC is discussed in detail below.

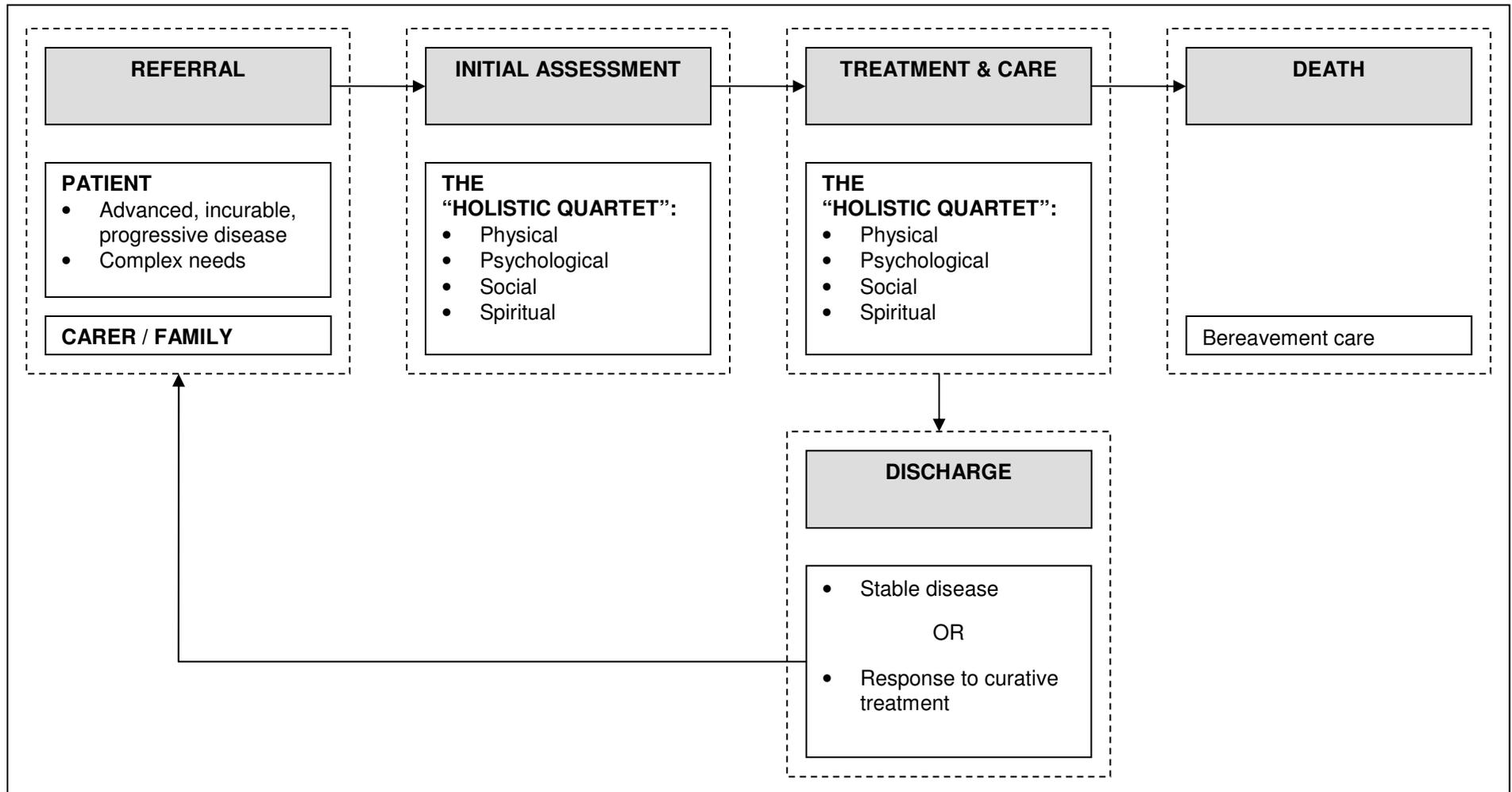


Figure 5.3 A conceptualisation of SPC need from documentary analysis

Analysis of observational and interview data

An alternative model of need for SPC emerged through my analysis of observational data. It is one in which the 'ideal' version of SPC has been winnowed down to a more focused and less holistic service within the context of resource limitations. The development of this model of need draws on a conceptualisation of SPC as a specialty built around the desire of its staff to 'act'. 'Doing' something for patients involves a focus on critical and changing needs, usually physical, but at times psycho-social. Whilst initial assessments remain relatively true to the idealisation described within SPC literature and policy, ongoing treatment and care places the physical, and the pharmacological, first.

I identified two key elements of need through my observations: the prevailing physical, and the critical psycho-social. These are assessed and responded to within an overall focus on the declining patient. Within this approach the physical domain is dominant, with patients requiring a certain severity of physical symptoms to enter into SPC. Furthermore, in practice any reference to spiritual needs is tokenistic. Thus the 'holistic quartet', whilst maintaining its presence in documentation, practice guidelines and even perhaps in the minds of SPC practitioners, becomes something very different in practice.

The declining patient

The declining patient was central to considerations of need for, and the practice of, SPC. As the documentary analysis showed, patients considered for care are those with advanced, incurable, progressive disease. This focus on change, on an inexorable path to death, was apparent in observed discussions of both new and existing patients. Decline was identified by

practitioners through three primary, linked, areas – disease progression, deterioration in condition, and cessation of active treatment.

The progression of a patient's disease, with for example an increase in the size of a primary tumour or the development of secondary tumours, was a key piece of information in presenting patients for discussion, or clarifying their current status:

R1: *Is the tumour growing?*

R2: *She hasn't been rescanned recently, they haven't really, the last scan they had for her was in June they said the disease had progressed and some of the mets in her lung have significantly increased in size, liver lesions have increased in size, the pelvic mass was unchanged and there is an overall progression of the disease.*

Home care meeting RS2 08Feb06

'Objective' markers of disease progression such as these scan results were frequently linked to observed deteriorations in a patient's symptoms, both physical and psychological:

He was up and dressed and sitting in a chair, but he was obviously weaker, frailer, thinner. Very low, tearful, worried about how he was going to manage as the disease progressed, which it is, obviously.

Home care meeting RS1 Team 1 18Jul05

A final marker of change was the cessation of active treatment, usually commented upon in the context of explaining the role that SPC were now taking in a patient's care:

...so it was my first visit there yesterday, and she's a lady who had a renal stent put in to hopefully improve her performance status to hopefully have some chemo and then she went back to clinic last week and they said, essentially, her performance

status was unchanged and was unlikely to change and so they don't want to see her anymore and it's over to us now.

Home care meeting RS1 Team 2 24Jun05

The interest in deterioration and change is clearly in line with documentary evidence that services are for patients with advanced, incurable, progressive disease. Its central importance in defining need for SPC in practice as well as policy is further highlighted by the observed discontinuation of care for patients who lack progression of disease or symptoms. Stability was an overwhelming reason for discharging patients from SPC, for moving them a category of need for care to one of no need. Whilst aspects of this were recognised within the documentary analysis, my observations found that the 'progressive' dimension often came to the fore when considering which patients should be receiving care. Patients discharged from the service frequently still had advanced, incurable disease, but if it was no longer worsening, their requirements for SPC may be questioned:

... [palliative care] deals with people who by and large are changing quite rapidly. They're changing at least month on month, sometimes week on week.

Doctor 1 interview

Having the 'potential to deteriorate' was used as a reason to keep patients on the caseload for now, in anticipation of decline. Those, however, whose disease or symptoms were stable may not continue to receive care:

Because I think actually CD probably we might be discharging, because he's got prostate with spinal cord compression, but actually he's not symptomatic and he looks like he could be around for a little while.

Home care meeting RS1 Team 3 17Jun05

Decisions to more readily discharge a stable patient, even one with advanced disease, from SPC were linked by one senior doctor to the resource limitations under which services were now working:

... because it's quite possible to have a group of people who are really very stable, and are trogging along just fine and all you do is go and have a cup of coffee with them once a month. Now, if you want to inflate your service numbers, that's one way to do it. But actually, viewed objectively, it's a waste of resources.

Doctor 1 interview

The prevailing physical

Meetings concerned two different categories of patients, new patients and those already under the care of the service. There were clear differences in how discussion formed around these patients. Presentations about new patients varied according to the style of each staff member, but the paperwork they referred to in recounting their initial visits tended to give some uniformity to content. In particular, initial assessments routinely comprised the 'holistic quartet' of SPC concerns – the physical, psychological, social and spiritual – and were reported to the meeting as such. In spite of this guiding framework, however, staff tended to focus in on the physical needs of the patient, with details of symptoms forming the bulk of the information imparted and discussed. For current patients, the primacy of the physical was marked. Discussions and actions centred on physical symptoms and their control. Additionally, decisions to accept patients to the service (particularly notable for inpatient bed discussions) centred on the physical.

This predominant focus on bodily functions and malfunctions was apparent within the diverse array of the symptom concerns which were discussed in observed meetings [Table 5.6]. The content analysis conducted to inform the

choice of a measure of need for SPC (discussed further in Chapter 6) found that pain, breathlessness, nausea and/or vomiting and weakness were the most frequent focus of discussions across both community and inpatient settings. Fatigue and constipation were also major concerns with community-based patients.

Table 5.6 Physical symptoms discussed in observed meetings		
Pain	Ascites	Anorexia
Breathlessness	Fatigue	Sore or dry mouth
Nausea and vomiting	Drowsiness	Jaundice
Weakness	Cough	Bleeding
Confusion	Diarrhoea	
Constipation	Oedema	

Some of these symptoms, particularly weakness, confusion and drowsiness, have a psychological component. However, the psychological and social components of these concerns were rarely discussed. Instead, reporting of physical problems usually led into discussion of appropriate pharmacological responses. Staff engaged in long debates on the prescribing of medication, to the extent that meetings could primarily be concerned with pharmacological approaches to physical needs. Medication concerns could be brought in very rapidly following the introduction of a patient for discussion, as the following extract from a new patient presentation shows:

He's a 78 year old man with an astrocytoma, grade 3, who became much less well in May and we then got involved. He basically became immobile and confused within the space of a week, and his GP put him on Dexamethasone but on a sort of gradual high dose. So he actually went up sort of from 4 mg to 10 mg to 14 mg, but he's now been on 14 mg, since the end of May and he's still bed bound.
Home care meeting RS1 Team 1 23Jun05

Depictions of patients' symptoms and potential pharmacological responses to them were nearly always presented first to the meetings. This reflected the

pattern of patient assessments, where physical information was routinely gathered prior to other domains of care, ensuring the physical was known even if other dimensions were missed:

Because he can only speak for a limited amount of time before he vomits, I didn't get onto spirituality, social, etc.

Inpatient meeting RS3 26Jan06

The dominance of the physical was further reinforced by the way in which staff controlled talk within meetings. Patient histories commonly started with the physical, briefly mentioned other aspects, and were then brought back round to the physical by the presenter. Interjections by other team members were also used to return the focus to the physical, in spite of other potential dimensions of need which may have been raised. In the following extract from a home care team meeting, a nurse only briefly presents a new patient's psycho-social concerns (given in response to a routine question prompted by documentation requiring completion), before returning to the original topic of the patient's pain and its control. The physical focus is further reinforced by another team member taking up the pharmacological topic as the crucial point of information for discussion.

R1: *He's got no real goals and expectations, except one long term goal of continuing to be. He's going to his granddaughter's 16th birthday party and a wedding. But we discussed his Oramorph. He said when he first started it he found that it was very helpful but as time's gone on it doesn't help so much.*

R2: *What's happened to the dose over that time?*

Home care meeting RS1 Team 1 23Jun05

Some staff interviewed argued that by focusing on and dealing with the physical aspects of a person's illness (that is, by controlling their symptoms),

they were more able to start addressing the more existential aspects of their illness experience. So, by an initial focus on the physical, SPC providers were freeing both themselves and the patient up to move on to address the more holistic psychosocial and spiritual dimensions of care. However, whilst one doctor felt that SPC should be multi-dimensional, he acknowledged that it is unlikely doctors would address all aspects of care:

Well I think the thing about SPC, is that it is holistic, or should be. So that is should have the facilities to deal with people in the round. Now, for me, actually, the absolutely prime thing is the physical, because I'm a doctor. And so that's fundamentally what I am supposed to be good at.

Doctor 1 interview

If doctors concern themselves with the physical, other dimensions of SPC may be addressed by nursing and social work staff regarding these aspects as part of their role. This is, of course, the foundation of multi-disciplinary practice. However, my observations suggested that, regardless of the skill mix present, the primary focus of meetings remained on the physical.

The critical psycho-social

The prevailing physical orientation of work could, however, be disrupted by acute psycho-social concerns. In such situations, overwhelmingly urgent social or emotional situations became the focal point of SPC work.

Addressing these psycho-social problems subsequently freed up provider's ability to move back into the physical domain once the immediate crisis had passed. This, of course, is the opposite of that suggested above – that dealing with the physical enabled a switch in focus to other domains of need. In less volatile situations, psycho-social needs of patients were predominantly dealt with secondary to their physical needs.

Prioritisation of psycho-social needs typically came from crises related to a patient's housing, financial or family circumstances. These complex issues were time-consuming for SPC providers, both within meetings and on a day-to-day basis, as they attempted to ameliorate the situation either themselves or with the help of other specialists. For example, one nurse was spending a large proportion of her time trying to work out how or if one of her patients could return to Portugal, from where he had recently arrived in the UK. His four young children were still in Portugal being cared for by a friend, his wife was with him in the UK but, like him, spoke little English, and they were both living with a friend whose children were sleeping in the living room to accommodate them in her flat. He was now mostly bed bound but did not wish to return to Portugal as he felt there was no treatment there – although his tumour was not chemo-responsive and he was not receiving active treatment in the UK either. In presenting the patient's circumstances to her colleagues, the nurse first touched on his physical symptoms:

...just his gross abdominal distension, really, it's really, really taut, it's quite hard and I presume very uncomfortable for him, really, stretched so his skin is really shiny, almost like it would just break and he's quite emaciated.

Home care meeting RS2 01Feb06

However, the physical was dealt with swiftly to focus on how to resolve the multiple social issues: the need for effective translation, his uncomfortable living situation, the possibility of his return:

Maybe, but I'm thinking will he afford the flight, will he afford the flight to go back because he doesn't really have money [...] I've been trying to find out what entitlements he would have, if any, as an EU national and I made a few calls, you know.

Home care meeting RS2 01Feb06

Strained or problematic family relationships were also a common focus of attention. Whether these situations were heightened by the illness of a family member, or caused by the illness, they could become the dominant perceived need of the patient at that time. Discussions would then cover very detailed assessment and feedback of the relationship issue and suggested interventions to improve the situation. For example, one patient with advanced cancer and a young daughter was living with her mother as a result of her illness. Staff were concerned about the relationship between them and the impact it was having on her symptoms, and in the presentation to the meeting of her case her primary nurse outlined in some detail her assessment of the situation:

She's actually spending more than 50% of her day in bed. It's difficult to tell whether that's a direct result of the illness or not. I'll discuss that when I get to her mother. [...] She has a seven year old child and she's living with, moved back with her mum for the time being, because she's not well, and I spoke to her and her mother both separately, and they have never got on and they are arguing and a lot of the arguments are around her mother trying to discipline her [grand] daughter who's misbehaving. [...] Her mum sees [patient] as being very lazy, that she doesn't make any effort to get up and do anything, [patient] says she doesn't feel like it. But it's difficult to know, you know, how much of it is directly due to the illness and whether some of it is perhaps due to psychological reasons, that she is perhaps depressed.
Home care meeting RS1 Team 3 22Jul05

A patient's psychological needs could also become critical quite quickly and displace the focus on the physical, prompting more detailed assessment and referral to specialists.

R1 *So today I was trying to assess her psychological state because the nurses say she's been in tears quite a lot.*

R2 *For a week, they said.*

R1 *[...] when things go wrong she just bursts into tears and everything's dreadful etc, etc, but I mean having said that, you know, she's been whacked with a whole load of disease all at once, all very quickly, really, so I'm not*

surprised, I just think she's probably not very good at expressing it, so I'll make a referral to [psychologist].

Inpatient meeting RS3 01Feb06

Psycho-social needs were not just confined to patients. Carers' needs rose to the fore when they were identified as not coping, leading to outbursts or immediate difficulties requiring attention and support.

She was hysterical, she was crying, she was screaming, she couldn't cope because he had deteriorated so quickly over the weekend. The fact that he was incontinent and she couldn't think of changing his pads, she couldn't cope with that at all because he's always been able to do things for himself. Anyway, I ended up having to help her to change him because she was just crying all the time.

Home care meeting RS2 15Feb06

The prevailing physical does not, therefore, entirely remove other domains of concern from provider's attentions. I observed that psycho-social crises and complex issues were responded to sensitively and with energy.

However, less visible psycho-social concerns of patients were not necessarily attended to in the same manner. As one nurse told me, the bi-monthly reviews of patients carried out in the MDT meetings were useful to ensure an issue was not missed for patients who were classified as just 'chugging along' (fieldnotes RS1 14 June 2005). For most patients who fell into this category, the domain of the psycho-social remained secondary to the physical.

The tokenistic spiritual

Discussions or assessments of patients' spiritual needs were rarely observed, in spite of spirituality being such an integral part of the work of SPC as identified through documentary analysis. Within RS2 and RS3, computer records updated during each patient review require a set pro forma to be

followed. This demands entries are made onto the patient record across all fields, including spiritual needs. The following two extracts reveal the usual response to this dimension:

R1: *Spiritual, anything?*

R2: *To be assessed.*

R1: *OK.*

R2: *Difficult to get round to those kind of things.*

Inpatient meeting RS3 1Feb06

R1: *Spiritual, continue to explore?*

R2: *Yeah, yeah.*

Home care meeting RS2 1Feb06

When assessments of spirituality were reported, infrequently at best, these were associated with religious denominations. 'Spiritually a Christian' (inpatient meeting RS3 26Jan06) was a typical response. I did not observe mention of spirituality outside of discussions prompted by the requirements of record keeping.

A new way of looking: quantifying the data

Trying to decipher the way in which patients were being presented and discussed was rendered more complicated by the different services included in my observation, and the contrast between new and current patients. How concepts of need were being applied in such discussions, and the dimensions which were prioritized, was not always clear from the coding frame I had developed thus far. Having moved from freestanding codes to coding trees, re-developed and re-organised several times, quantification of some aspects of the qualitative data was used to offer an alternative way of thinking about the content of discussions.

An extract from the data tables generated as the first step in this approach is given in Table 5.7. This shows a sample of the summarized content of one observed meeting of the RS2 home care team. Each patient presented to the meeting is identified, and information about their diagnosis and treatment, as told to the meeting, abridged. These summaries focus on the identification of major domains of need for SPC (physical, psychological, social and spiritual), alongside additional dimensions such as pharmacological discussions and the decisions taken within the meeting about appropriate next steps or care.

These tables clarified that talk tended to be concentrated on the physical and pharmacological domains of a patient's needs, with other dimensions of care (social, psychological, spiritual) covered less frequently. This reinforced my idea that the 'holistic quartet' was not applied in practice as comprehensively as policy documentation suggested.

Table 5.7 Example patient summaries extracted from RS2 home care meeting 18 January 2006

Patient	Type	Diagnosis	Treatment	Physical	Pharmacological	Psychological	Social	Spiritual	Carer/family	Decisions taken
SW. Female. 62.	New	Breast cancer, liver and bone mets. Pleural involvement. Hypertension.	Had lumpectomy 2001, chemo and radio. Further chemo and palliative radio.	Pain (liver and jaw), poor sleeping, poor appetite, occasional nausea, constipation	On Oramorph, Amytriptyline, Movicol	Son died in car accident in 1996, husband died 2004 - withdrawn/depressed ever since.	Does not speak English, son translates. Very socially isolated. Lives with son and his wife.	-	Son involved - lives with her and translates	To review by phone with son in two days time re pain and constipation. Chase GP to change Amytriptyline dose
BJ. Female. 47	Current	Anal cancer (recurrent)	Previous surgery. Considering radiotherapy - long delays in treatment unclear why	Pain, uncontrolled, interferes with sleep	On Amytriptyline, MST, Oramorph. Non-compliant	-	Lives with flatmate.	-	-	Long discussion re pain meds. Considering home doctor visit - will review next week
PD. Female. 87.	Current	End stage cancer, end stage congestive cardiac failure, dementia makes it difficult to assess	-	Denies pain. Breathless	On continuous oxygen. Antibiotics. Something for rash	-	-	-	Daughter gave up work to care - wanders at night, daughter v. stressed	None in meeting - CNS update
KC. Male. No age	Current	Sinus cancer	-	Severe uncontrolled pain.	Have made many changes to pain meds	-	-	-	-	None in meeting - CNS update
JG. Male. 70	Current	Colon cancer, liver and lung mets, suspicion lumbar mets (pt denies)	Recent surgery. Potential offer of chemo	Jaundiced. Potential infected abdominal abscess.	Long discussion re meds [antibiotics] causing jaundice or not. Other meds noted.	Possible denial of prognosis; anxiety re future.	-	-	Wife asks more re prognosis	None in meeting - CNS update

Representing patient summaries in graphical form helped to further clarify this. Using my *a priori* headings, graphs were constructed separately for new and for current patients in each research site to record the presence of talk within each domain [Figures 5.4 and 5.5]. These show clearly the importance of the physical and pharmacological, with staff discussing physical issues for 100% of new patients, and around 90% of existing patients across all three research sites.

There are notable differences in the prevalence of discussions around psycho-social issues for new patients and existing patients, with these issues receiving less attention for patients already under SPC. However, it is interesting that carers/families are discussed more frequently on average for existing patients than for new patients at RS1 and RS3. Variations between sites in the proportions of patients for whom the 'secondary' domains of need (social, spiritual) are discussed may be attributed in part to differences in the routine practices of each meeting. I now turn to consider the influence of these working practices on conceptualisations of need.

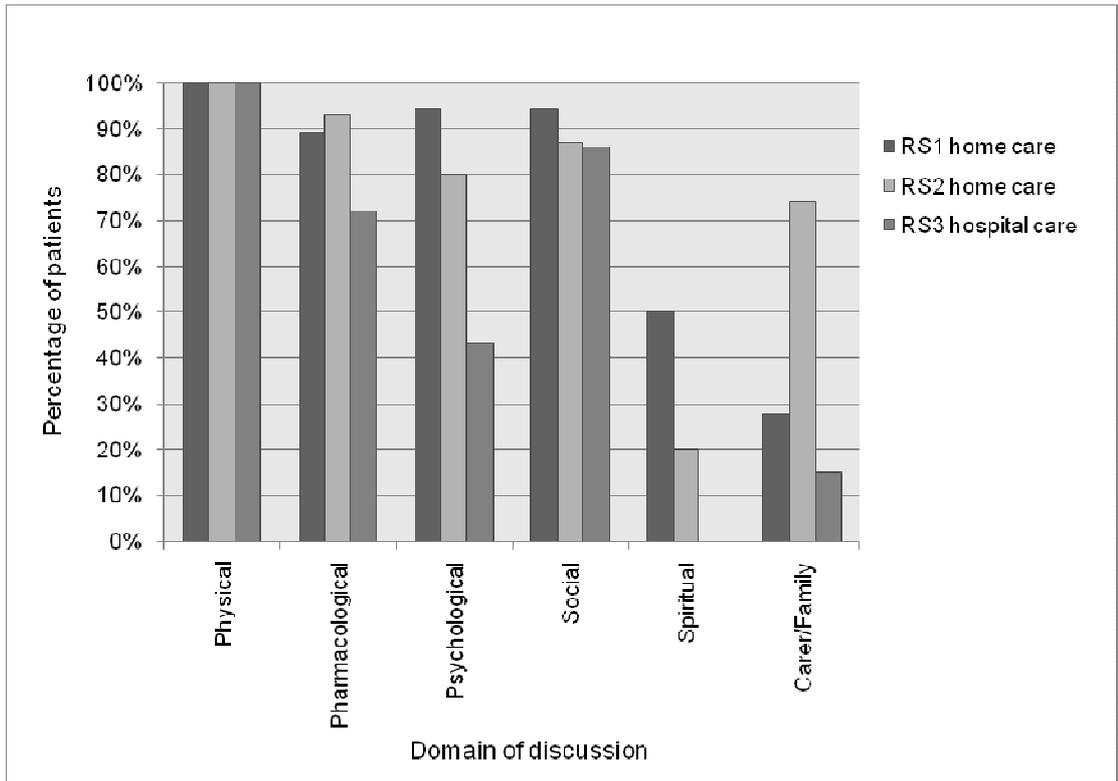


Figure 5.4 Domains of discussion for new patients

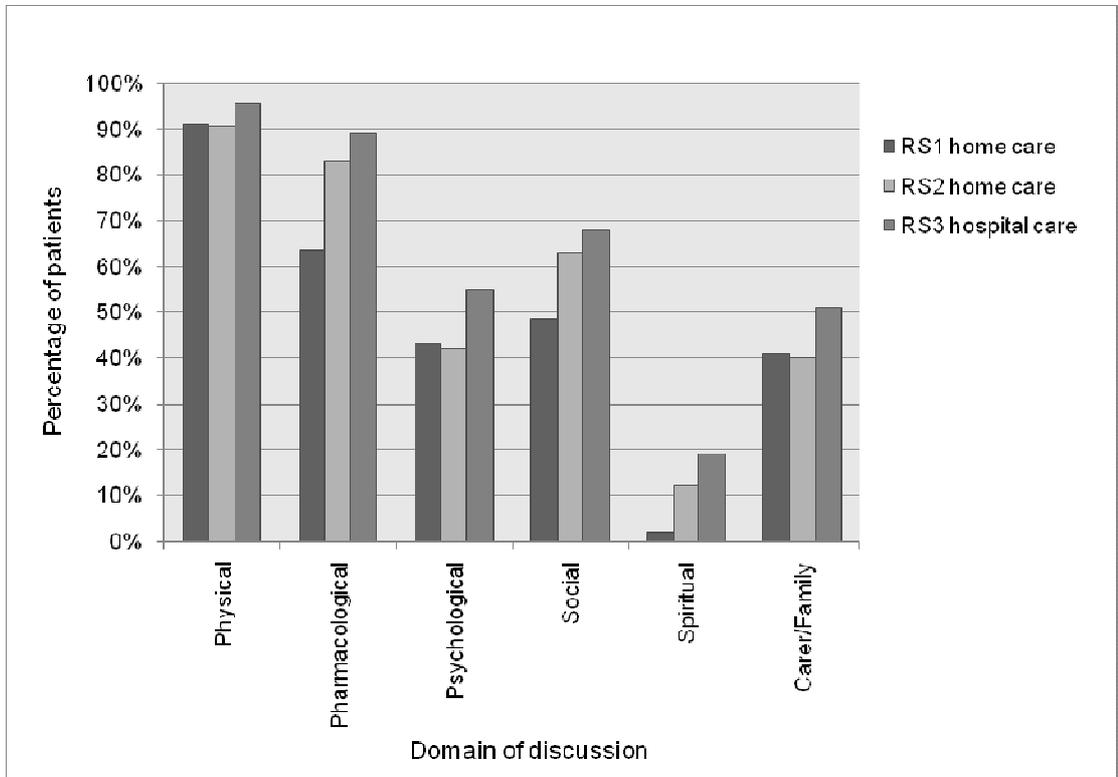


Figure 5.5 Domains of discussion for current patients

Documentation and discussions

As set out in the introduction to this chapter, contextual considerations are crucial when considering how concepts of need are derived. The process by which decisions about care are made or otherwise arrived at is a key factor in determining access. During the course of my research, I was therefore interested to see how practices between each research site varied, and the manner in which these practices shaped outcomes.

Meetings within each setting had their own unique structure and rhythm. In the RS3 hospital team, notification and discussion of deaths and discharges preceded issues arising and routine reviews of each patient currently on the caseload. For the RS2 NHS community team, new patients, urgent problems with current patients, deaths and potential discharges were discussed, with each patient additionally being presented for review every two months. Both NHS settings were heavily influenced by the requirements to keep up-to-date computer records for all patients, and each meeting took place in a board room with a computer to record changes as they were discussed. The community teams within the voluntary hospice (RS1) varied in their approaches to their weekly MDT meetings, but typically they discussed deaths and patients requiring immediate action or input, and then took it in turns to present patients for review. These often had a more informal atmosphere than the NHS meetings, taking place in the team's own offices with comfy chairs drawn up and a tea tray set out.

The order of discussion in each meeting, as set out above, was guided by the working policies of each setting. Additionally, the manner in which each patient was presented within the meeting was shaped by the setting's choice of patient assessment tools and records. Thus, as each new patient was presented to the wider team by their primary nurse, their history was

constructed with reference to notes taken at the time of initial contact. Staff recounted patients' background and circumstances alongside detailed summaries of medical history, current treatment and symptoms. One example of this 'new patient presentation' is in Table 5.8. Throughout this presentation, questions from other team members are answered after checking the patient's notes file for the relevant detailed information. As this particular history progresses, the nurse recounts symptoms directly from the assessment tools she used – thus, we hear her say 'pain wise', 'breathing wise' as she progresses through her file. These assessment tools comprehensively cover the 'holistic quartet' of needs. Here, we learn about the patient's family, their feelings about his illness, his fears about the palliative care referral and his day-to-day living circumstances, as well as his current medication and treatment. Thus, for new patients the comprehensive ideal of need for care is reinforced by the choice of initial in-depth assessments and reference to the documentation of these.

Table 5.8 Example new patient presentation
Home care team meeting RS2, 18 January 2006
<i>OK, EF was a gentleman who was referred by his GP for palliative care. He's been treated at [hospital] for cancer of his lower rectum. I've got very little information, I'm still trying to get some more information from the [hospital] on him, so most of my literature so far is based on what he's told me [...]</i>
<i>When he was diagnosed with lower rectal cancer, it was decided that he wasn't suitable for surgery or for chemotherapy because the chemotherapy may be toxic so he had radical radiotherapy which ended last year. [...]</i>
<i>They'd obviously discussed with him that he wasn't able to have any more treatment and from what he, his son felt that he'd taken that very badly, really. It sounds like they'd already had a previous conversation with him about having more, having palliative referral to [hospice] and he'd taken that very badly I think and thought that he, um, was going to die rather imminently. Um... [...]</i>
<i>His wife, G, used to be practice nurse at the GP's surgery [...] And she did make</i>

it very clear to me that she was a nurse so some of the issues around care and stuff she actually wanted to do herself, so anyway.

But the gentleman looks older, actually, than 74 because of all the different illnesses that he's got and had. [...]

Pain wise, initially he said, oh no I don't have any pain at all, I'm fine, no pain, then as we went on further it transpired that actually he has quite severe arthritis in both knees and he's on Tramadol and Diclofenac for that, [...] Breathing wise he's got quite severe problems with angina, obviously his heart, and that causes him to have quite severe problems with getting about, if he does any exertion so he could only walk about 100 yards very slowly and then he really was very ill and short of breath. He is managing his activities of daily living except that he needs help getting in and out of the bath [...]

His appetite's been... and he's lost quite a lot of weight really in the last couple of months, about 6 kilograms [...] He does feel nauseated at times, but his main problem which I think ties into that is that since the radiotherapy he's had a problem with passing mucus and we had a long talk about how, you know, it's difficult to decide whether someone's constipated or got overflow or had diarrhoea, so I explained that his thing was that he probably had constipation with overflow problems rather than diarrhoea, and every now and then he passes some mucus which I think is harder to control. He had Loperamide but he hadn't been taking much of that more recently, and he's had Lactulose as a laxative and he had, um, not been using that very often, um, and that was about it and then he changed from Co-codamol to Tramadol [...]

Um, yes, so that was him really. He clearly had taken it badly that this appointment had been made, he talked quite a lot about that and how he had been very reluctant for his referral to palliative care so basically I just took it in a very practical sense [...]

He lives with his wife and also a son who is called, um, I think his name is H. His other son is married and lives in [county] with his children, and it sounds at some point they all talked about moving to be nearer to the son. It's a very large house just off [road] and he's getting DLAs which he's been getting since his bladder operation [...]

Subsequent reviews of each patient's needs are rarely so comprehensive, as Figure 5.5 (page 192) shows. Future discussions of patients are not rooted in the accepted norms of presentations of new patients, with their routine

coverage of multiple domains of concern. Instead, subsequent presentations of patients to a meeting arise either because of pressing problems, or because they are due for review. In both these cases, the framework used for presentation is less formalized and more fluid. Thus, when the patient whose history is presented above [Table 5.8, page 194] comes up for discussion in future meetings, talk is focused on his immediate physical needs:

I spoke to his wife on the 10th of the 2nd and they were very anxious because his faecal incontinence seemed to be getting worse [...] I had arranged to go and visit them on Friday, then overnight, the weekend nurses got a call to say that he wasn't very well and he'd got a rectal abscess so the doctor had been out and things like that and he was still leaking faecally and he'd probably had a stroke or something.

Home care meeting RS2 15Feb06

I observed that admissions meetings for inpatient hospice beds also relied on a routine of the comprehensive patient history as the basis of their decision making. However, with only a short referral form to refer to, and many patients to be reviewed and beds assigned, histories (whilst inclusive) are tightly worded and brisk:

So, Mr JK. Um, very urgent referral, please consider as discussed on the phone. OK. This is a 72 year old gentleman. He's widowed. He's got inoperable pancreatic cancer. He speaks little English, so as an interpreter would be helpful but his son does speak good English. His next of kin is his son. He's being referred for pain and symptom control, emotional and psychological support, and carer support. Um, also, yeah, want to be admitted for terminal care. The patient is currently in hospital, bedbound. Referral asap. He is MRSA positive, he's got metastatic disease in his sigmoid colon. He's had a [inaudible] procedure. That's major surgery where they cut one bit out and they join with one of the ducts to the lower part of the colon so you bypass the mass. Hypertension and COPD as well. He's dying, he's in pain, he's got breathlessness. He's got fatigue and drowsiness, ascites, sore mouth, and not sleeping very well. The family and patient were desperate to go back to [country of origin]. Now realise he's too poorly and very keen for hospice admission. Oh, how sad. They've missed the boat. OK. 3 for severe physical, sorry, 2 for moderate

physical symptoms, 2 for moderate emotional spiritual problems, and 3 for the carer, 1 for lives alone, and 2 dying within 48 hours.

Admissions meeting RS1 8Jul05

The score assigned to each patient on aspects of need for care reduced the patient's circumstances to a quantifiable urgency. It also typically represented the end of that patient presentation. Again, talk is here shaped by the requirements and coverage of documentation and policy.

The most explicit examples of the impact of documentation on the content of meetings were observed at RS2 and RS3. Here, computer records on each patient were updated during meetings, leading to exchanges such as the following:

R1: *[At computer] So physical, all I've got from [nurse] is p.r.n. Oxynorm for home.*

R2: *You can wipe that off, say, um, some discomfort in his scapula, prefers to... on paracetamol t.d.s. and p.r.n. Oxynorm and total bed rest at the moment, I think that's enough.*

R1: *Psychologically brighter. Citalopram 20mg started, aromatherapy, does that sound...?*

R2: *He's having, yeah...*

R1: *So is he psychologically...*

R2: *He's fine, pretty much.*

R3: *Maybe from last time.*

R1: *Yeah*

R2: *Compared to what he was last time, he came in said I'm depressed I do need something.*

R1: *But they're both a little bit anxious you said.*

R2: *Oh they are, they're talking about it, I think. They [inaudible] this time and whereas the wife was saying don't give him the bad news, and she's still saying, she's more saying, stagger the information now rather than... which was quite interesting but I had a good chat with her.*

R1: *Mm hm, social, lives with wife, for benefits DS1500 refer back to [community SPC] team.*

R2: *Yeah, social just lives with wife.*

R1: *Mm hm. Um...*

R4: *We have done a DS1500 did we?*
R1: *No, I don't think so.*
R2: *I need to check that, whether they have done.*
R1: *Spiritual to explore.*
R2: *Did you leave the DS1500 in that social one? Check DS1500?*
R1: *Is that to be done, check?*
R2: *Yeah.*
R1: *Yeah, spiritual, anything, or I've got to explore. Information needs, fully aware.*
R2: *Yeah.*
R1: *And then, under carer concerns from last week, wife is anxious, declined formal support, happy to talk to nurses when feels she needs to, doesn't want him to have bad news [inaudible] on multiple bereavements in families in last few years. Is that still all applicable?*
R2: *Yeah, that has to stay on I think.*
R1: *OK. Done?*
R4: *Have you saved it first?*
R1: *Yes, I am doing it, both saving it and printing, it's the printing that seems to be the problem. But yes.*
R4: *OK, the next one.*

Inpatient team meeting RS3 15Feb06

These records are an important part of the care provided to patients. They set out what has happened to date, and guide what actions are taken in the future. Their content reflects the publicly agreed domains of action for a service. The choice of assessment tools, for example, will influence the nature of the information gathered about patients, and the subsequent course of their treatment and care. Thus, they both shape and record the actions taken outside meetings as well as the talk within meetings.

Yet the comprehensive nature of both policy and practice suggested by these records does not necessarily translate to a consistently holistic approach throughout the trajectory of a patient's care. Initial assessments are rarely revisited in the same depth, and domains which are seen as less urgent or important may receive only perfunctory mention. Whilst talk in meetings is

underpinned by previously gathered information or the update of this information, these policies are not able to fully dictate practice. The typical content of a presentation about a new patient, a review and an urgent patient problem reveal how a practitioner's focus may change throughout the course of a patient's care, from getting to know and understand the situation to simply dealing with the immediate pressing concerns. The implications of this for ideas around need for care are considered further below.

The importance of 'doing'

Throughout my analysis of the data, I considered dialogue and events which may indicate 'non-need' for SPC: factors or components which in the minds of SPC providers meant patients did not require their input. As already noted, the unchanging physical (the stable patient) was the dominant factor in a patient being regarded as not having a need for SPC input. In my fieldnotes following one home care meeting, I wondered whether this link between stability and lack of need was about the staff's expectations about their role – about the need for them to do, including the provision of advice:

The first patient to be reviewed was very interesting as there was a query whether to discharge them or not. They had quite a long discussion about her diagnosis, treatment for cancer, and current situation. This time I picked up that discharge decisions are focused often on what the CNSs do when they visit. So – the question was that the CNSs didn't do anything when they went to see her – therefore should she be discharged? This inability to do anything, backed with an understanding that her disease was not at this time actively progressing, resulted in the decision being made to discharge her.

Fieldnotes RS1 28Jul05

The displacement of a focus on the physical by psycho-social concerns when they are acute and pressing suggests that 'doing' is not confined to reviewing and addressing symptoms. My observations suggest that a

definite focus of action – relieving the pain, improving breathlessness, sorting out an insecure living situation – is what motivates and rewards staff. More elusive dimensions of spiritual needs and concerns, harder to assess, address and to resolve in a situation of impending death, may not be encompassed by day-to-day actions in spite of claims to the contrary. There is also the issue of the expertise staff feel they have, discussed further below.

Contextual constraints

The diversity of aspects of care SPC aspires to address is ideally addressed by the complementary skills of a multi-disciplinary team. Such teams within the SPC setting may encompass social work, chaplaincy, psychotherapy, complementary therapy and psychiatry alongside medical and nursing expertise. However, at two of the research sites there were vacancies in social work at the time of data collection. Meetings observed were primarily attended by medical and nursing staff, and thus discussions centred on the competencies of these professionals. As one interviewee said:

And I think here, in particular, there's been quite a lot of silo practice, in that the domains of care have sat very much with, you know, psycho-social sits with social work. And if there isn't a social worker member in the team meeting, then those needs are often not addressed. So whoever's not there, their particular profession doesn't get talked about. So it does become very symptom focused, because symptomatology is a, it's a tangible that nurses can work with. If they feel uncomfortable with psycho-social issues, they can hide behind it.

Interview nurse 2

The limitations imposed by a lack of staff were particularly severe within the NHS environment. High staff turnover and ongoing vacancies were compounded by a shortage of equipment and beds. Within the voluntary sector pressures were also evident, with very high bed occupancy and

financial targets to be met. Additionally, a lack of information and poor communication could limit the care available to patients.

The structural constraints on day-to-day working, along with role expectations, inevitably influence the orientation of SPC work. The potential for 'fire fighting', a focus on the dominant issue which requires attention, is more marked when staff do not have the luxury of unlimited time in which to address all aspects of care. This is of course a situation to be found across many if not all medical and nursing specialties. However, it is particularly apparent in the light of the claims that SPC is broad in approach.

Maintaining such holism becomes increasingly challenging if the time is not available to address all areas of concern. Rather than a lack of care, providers may alter the dimensions or quantity of care to make ends meet. Visits may be less frequent and/or shorter to manage the caseload; requests for inpatient admission may be deferred until beds become available. And, of course, care may focus on the physical and the immediate if that is within the expertise and capabilities of the available staff on the SPC team:

You know, you can always do more with more resources.

Interview nurse 1

Towards a new model of need for care

The first model of need for SPC I derived presents SPC as holistic and multi-dimensional, moving from referral through to initial assessment and ongoing care whilst maintaining an interest in and concern for all aspects of a patient's, and their carer's, needs. Based on observational data across all three settings, I now present a second alternative model which suggests a more narrow focus on 'doing'. To enter into SPC, patients must clear a

'physical needs' hurdle, with advanced disease and a high level of physical symptoms agreed by SPC providers as rendering that patient suitable for their care. The provision of SPC then primarily addresses physical needs, although it may also focus on psycho-social crises when these interfere with the ability to address the physical. Patients must be actively progressing to be seen as having a need for care, and must maintain this inexorable decline even in the face of constant interventions to improve their physical state. The role of resources is key, within both the voluntary and NHS services; limitations on the availability and skill-mix of staff, beds, and equipment constrain the delivery of care across all settings of care.

This second model is illustrated graphically in Figure 5.6.

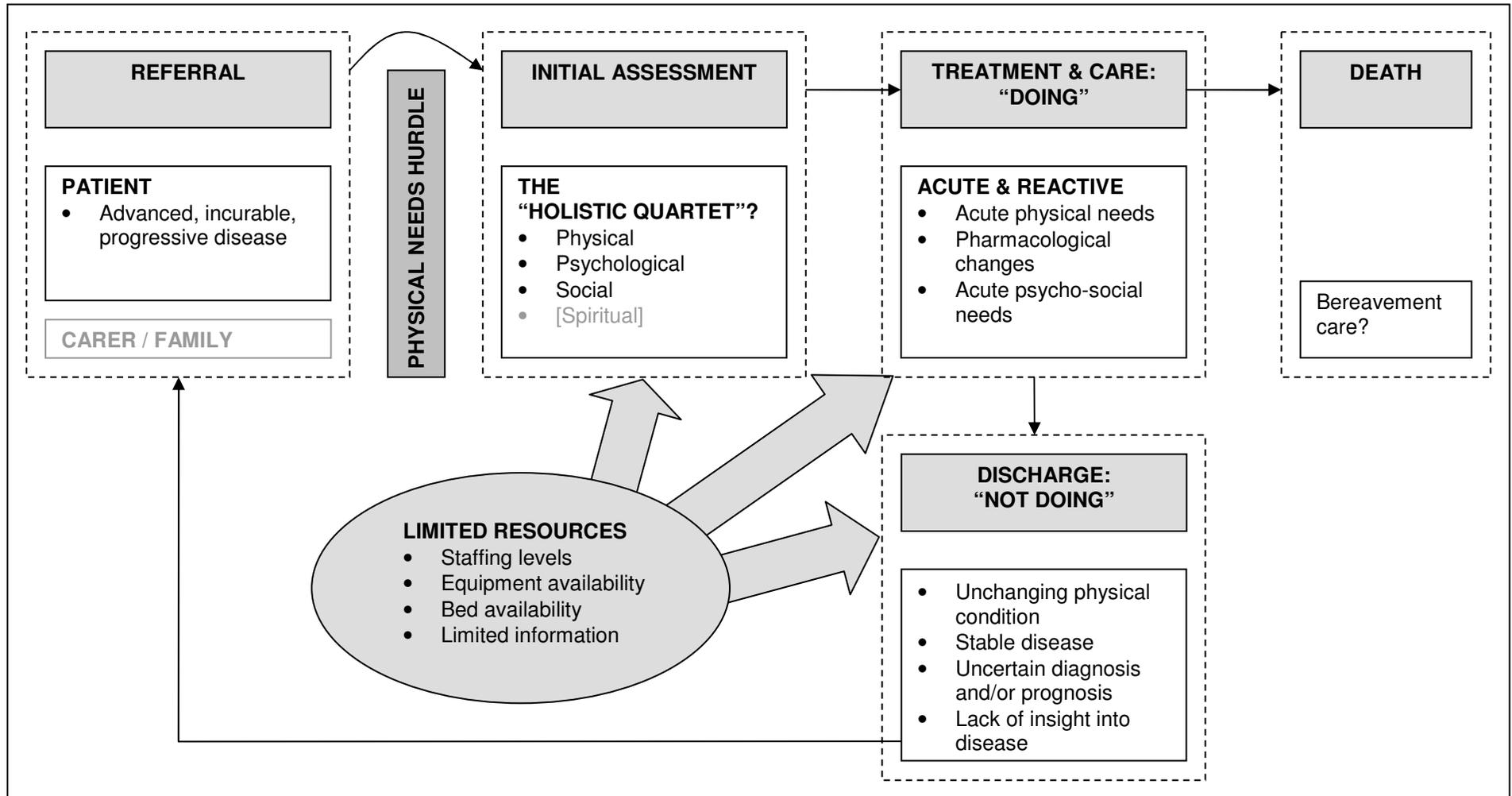


Figure 5.6 A conceptualisation of need for SPC from observational data analysis

The role of age and other patient characteristics

When I started fieldwork for this study, I set out to investigate not only concepts of need for care, but also what other factors may influence access to and receipt of SPC. In my original formulation, I thought of these as ‘non-need’ factors – dimensions which could not be assigned to ideas of need, but which even so may be influencing access to care. These included patient characteristics such as age.

Of course, in the process of this research I quickly realized that ‘non-need’ was an almost impossible category to apply to such factors. Additionally, the dichotomy of need or no need was potentially unhelpful when services may respond to pressures by limiting the amount or quality of care provided, rather than simply denying care. The complexities of how patients were presented, categorized and responded to meant that it was entirely possible that characteristics such as age could form part of a provider’s concept of need, even if this formulation was not set out in policy or regarded as ‘acceptable’ in the pursuit of equitable access.

Within the meetings I observed, the age of each patient was routinely given at the start of any presentation about them, usually in the format of ‘[Patient] is a 74 year old lady with [diagnosis]’. This background information about age, whilst obviously perceived as an important piece of information, usually passed without comment. However, on a number of occasions where patients were younger, staff reactions implied a feeling of tragedy in relation to their age and circumstances:

R1: *Um, [patient] was put in [hospice] yesterday afternoon but she’s died this morning.*

R2: *Oh, OK.*

R1: *And [nurse] has gone out there now because the family are distraught, it's a 45 year old.*

R2: *[Gasp]*

R1: *Mmm.*

R2: *Oh. OK. Oh dear.*

RS1 admissions meeting 07Jul05

R1: *And then...this lady too.*

R2: *Yeah, she's been on [hospice ward] before.*

R1: *Another youngish lady, isn't she?*

R2: *Yeah, she is – very sad.*

RS1 admissions meeting 28Jun05

Comments were infrequently made in relation to the older age of a patient.

Where they were, it was usually to emphasise that the patient was, in spite of their age, still lively and active:

R1: *How old is he? Sorry I missed that.*

R2: *He's quite ancient. He's 89 but doesn't look it and is a bit of a charmer, you know, you can see that he's obviously been a bit up to no good throughout his life. Um...*

R1: *Good for him.*

Home care team meeting RS1 Team 3 22Jul05

Um, he was born 1921, so that makes him about 84, 85 – and he's a very good 80 year old. He's very much out, walking - he goes away on holidays.

Home care team meeting RS1 Team 4 16Jun

There were was some suggestion within the meetings I attended that attitudes to age could translate to a greater level of care offered to younger patients once they were on the caseload of the palliative care team. A word of caution sounded by a consultant during one home care team meeting highlighted concerns that SPC may be requested to take on patients who had issues due to their age rather than their illness:

R1: *Well we need to watch her because we haven't got a confirmed diagnosis of cancer...*

R2: *we haven't...*

R1: *...so she is an elderly lady like a lot of elderly ladies out there. So, much as we can make a difference I think we need to also maybe on our first review sort of work out what our input's been and what specialist palliative care side of things has been.*

Home care team meeting RS1 Team 4 16Jun05

One interviewee directly stated that the palliative care service as a whole may be more likely to 'make more of an effort for a younger person.' They went on to say:

I sometimes notice that we're much more likely to try and put a younger person in a side room – oh yes, they're young they'd want their privacy, but actually there's no real logic behind that. Um, often you know – if there's children involved then you know we think it's nicer for them to be tucked away, but yeah – I certainly think there are inequalities there.

Interview Doctor 2.

This was borne out by my observations – as I wrote in my fieldnotes following one admissions meeting:

The expectation was that a side room would be better for her – she was 'a young patient'. [...] the very obvious message from [staff member] is that if she had a single room available she would put this patient into it and no reason was offered other than the fact she was 'young'.

Fieldnotes RS1 28Jun05

This placement of patients – whether in a bay or in a private side room, and on which ward – was an important part of the admissions discussion process at RS1. The complexity of assigning the 'right' place to patients who had been referred for an inpatient bed led to often lengthy discussions about who should go where and when. Side rooms were conceived as a limited and

valued resource for patients who had 'something significant' about them which may indicate a need for this level of service. Whilst reasons for the need for a side room were usually medical (the presence of open wounds or diarrhoea, for example) or social (young children), I also on one occasion observed the following exchange:

R1: *Mmmmm. Mmmm. Think he'd be alright on a bay?*

R2: *Well – we've not got any choice.*

R1: *Yeah I mean or should we wait for a single room for him?*

R2: *Why? Because he's a doctor?*

R1: *Mmmmm. Sorry!*

R2: *[laughs] Don't apologise! I think we should give him the choice.*

R1: *OK.*

R2: *I think we should say there is a bed today but it is in a four-bedded bay.*

R1: *OK.*

R2: *We can't guarantee a side room this week.*

R1: *Yeah, that's fine.*

Admissions meeting RS1 30Jun05

I was not able to gather statistical data on the proportion of patients who waited for access to inpatient SPC in relation to age. However, from attendance at admissions meetings my impression was that younger patients were commonly assigned a bed in preference to older patients with the same priority score.

These observations demonstrate how patient characteristics, outside of the 'holistic quartet', may determine the level of service offered to them. It is possible that aspects such as age, in the practitioner's eyes, simply reflect different patient circumstances requiring different levels of input, such as a requirement for greater psycho-social support due to the loss of income for those who work or because of the needs of young children. Yet it is also

possible that that there is a more subtle categorization at work, with characteristics forming part of implicit concepts of need for care.

5.5 Discussion

I have constructed two different concepts of need for SPC. My first, derived primarily from documentary sources, represents 'the ideal' (to use David Hunter's terminology ³⁰² p68) model of a clear pathway to and through holistic care. Patients requiring SPC will have an advanced, incurable and progressive disease with complex needs across a holistic quartet of domains: physical, psychological, social and spiritual. Need for care is thus comprised both of diagnostic and symptom dimensions, and the patient is viewed in totality along with their family and friends.

My second model of SPC need is based predominantly on observations of the day-to-day decision making and workload management undertaken by SPC staff. It represents a more winnowed down and reactive approach driven by the immediate issue of concern, usually physical, sometimes psycho-social. Care focuses on the acute and the changing. In spite of SPC's stated focus on holism, symptom control rises to the fore – a phenomenon observed in the wider medical approach to those with life-limiting illness. ³⁰³

Additionally, there is some suggestion that patient characteristics, including age, may influence access to care, and in particular the quality of care on offer. However, the evidence provided for this in the current study is limited.

Limitations

My use of a focused ethnographic approach was well suited to the development of conceptualisations of need for care. Commencing with clear

parameters of the phenomenon of interest enabled me to effectively target data collection to fulfil the study aim. Setting the focused ethnography across three providers enabled me to compare and contrast observations and develop a more rounded model.

I developed good working relationships with staff at all sites, and this enabled me to undertake useful informal discussions as my ideas developed. Staff appeared to feel relaxed with me present and continued with their normal working routines, for example within the RS1 office. At meetings, initial self-consciousness about being recorded appeared to dissipate rapidly, although of course I cannot know if certain things were said or done differently as a result.

The analysis undertaken used different analytical approaches to question the data from a number of angles. The challenges I felt in attempting to move beyond a purely descriptive analysis of the data to build a model of need were ameliorated by the freedom, within a pragmatic approach, to adopt new techniques (such as data quantification) to help me to answer the question at hand.

Whilst ethnographies are by their very nature situated within one particular context, it is useful to understand how their findings may be generalisable to other settings. My primary research site was a large and relatively well resourced provider of care, which may perhaps have an impact on the model of need I built. Additionally, models of care may differ in rural areas where service provision is affected by the challenges of serving more disparate populations.

My analysis would be richer if I had drawn on additional sources of data. As is the nature of focused ethnographies, I concentrated on particular sources of information – documentary, staff meetings, and interviews. My work could have benefitted from further observation of the routine working practices of SPC staff. In particular, I observed that decisions on patient need are frequently taken by staff alone, without consultation with others. More in-depth interviews and observation of daily working life may have enabled me to question this further.

Finally, time pressures did not permit me to return to participating providers to discuss and revise my data analysis in full. I held meetings with key members of staff to talk through my findings, but these did not form part of the analytical process. With hindsight, I feel my models of need would be stronger if SPC providers had been able to question my interpretations and offer their own. For example, teams may use a particular “shorthand” with each other when discussing patients, and their work may be more holistic than thus appears on the surface.

Comparison with other studies

There are few studies which have set out to conceptualise need for SPC. As discussed in Chapter 2, the majority of previous work has defined need in terms of diagnosis, the presence of symptoms such as pain or the perception of medical staff that patients are terminally ill.^{102;103;304} These definitions are employed in spite of the recognition that need for SPC is likely to be multidimensional in nature.¹¹³

Findings from an ethnography conducted within an NHS hospice in Southern England suggested that resource constraints led to the prioritisation of patients with distressing physical symptoms and those in

the terminal phases of illness, with a reduction in admissions for respite care.

³⁰⁵ In a study of factors influencing inpatient admissions in one London hospice, the emphasis was again on the physical, with the majority of admissions taking place for symptom control. ³⁰⁶ However, I have not located any studies within SPC considering the context in which decisions about need are made, and the content of these decisions.

Explanation for findings

I discuss my findings in three sections. First, I explore possible explanations of the two concepts of need for SPC I derived. Second, I try to account for my observations on the potential influence of age within SPC decision making. Finally, I draw these together to offer a further model of the context in which SPC takes place, and the importance of this in investigations of need, equity and use.

Need for specialist palliative care

Holistic ('ideal') formulations of palliative care need may be linked to Cecily Saunders' theory of 'total pain'. This influential concept holds that pain is not just about the physical aspects of patients' suffering, but encompasses mental distress, social problems, emotional problems and spiritual concerns.

³⁰⁷ Recognising the multidimensionality of pain becomes the first step in relieving it. This requires a multidisciplinary effort in which the team approaches the patient as a whole person. ³⁰⁸ The total pain concept underpins much of the development and suggested practice of palliative care. ³⁰⁷ However, attempts to attain this ideal may be ambitious. One research team, in their analysis of the practice of SPC, suggested that:

*Each caregiver involved in the caregiving process of terminally ill people must be ceaselessly concerned about the quality of the care... the quality of the moment is of utmost importance and should not be endangered by a caregiver's shortcomings.*³⁰⁹

The danger with such demanding requirements is that they cannot be realized in practice. Equipping individual caregivers with all the skills required to address 'total pain' is challenging. This is why multi-disciplinary teams form the basis for the SPC approach, with each staff member offering expertise in one or more areas (e.g. medical, nursing, spiritual, or psychological care). However, as my observations showed, SPC services do not always operate on a multi-disciplinary basis. In particular, difficulties in staff recruitment or funding in social work, psychology and spiritual care mean that needs in these areas are less likely to be recognised and addressed.

As a result, need for SPC may be re-framed by what staff are equipped to respond to. As one of the interviewees stated, if the expertise of medical and nursing personnel lies in the relief of physical symptoms, this becomes their primary activity and their goal. Further, providing ongoing emotional support to patients and their families within palliative care may be challenging for SPC staff. One focus group study of the experiences of new SPC nurses found that the emotional difficulties of palliative care led them to question how long they would be able to remain within the specialty.³¹⁰ The need to protect themselves from emotional distress and maintain some distance between work and home life may also, therefore, reduce staff willingness to provide psycho-social support without receiving adequate support themselves. Thus, whilst the stated aims of SPC (and thus initial patient assessments) remain holistic, a focus on the physical domain of work may lead to an implicit re-negotiating of patient need to a narrower, more

symptom-oriented concept. This is borne out by the perception of the Chief Executive of Help the Hospices, who in 2000 wrote:

I read of increasingly short bed stays as complex physical problems are prioritized over other, equally complex but more drawn out and not so scientific social or psychological needs. Has it become the case that a carer driven to severe distress, if not near suicide or murder, and crying 'help', is less likely to obtain a bed for planned respite care for their loved one than is someone who needs to have their drugs balanced in order to control pain, particularly if the former is old and the latter young? ³¹¹

However, Culyer and Wagstaff argued that a necessary condition for a service to be needed is that it should have a positive impact on the health or state of the individual. ³¹² This suggests that a need for care can only exist in domains to which staff can effectively respond. The evidence of effectiveness of SPC is limited; reflecting my observation above, what evidence there is tends to be confined to symptom relief. ²²³ This is not necessarily a problem. As a relatively new specialty, it is possible that SPC is in the process of working towards its aspirations of a holistic service, underpinned by high quality evidence of impact on all domains of patient and carer need. In the meantime, the work undertaken by the nurses and doctors who predominantly form SPC teams may have an excellent effect on the relief of pain and other important symptoms at the end of life.

In considering additional explanations for the move from the 'ideal' to the 'actual' model of need, I reflected on the process by which decisions are taken which shape need for care. Choices about care are made by providers within the context of managing their workload on a daily basis. ³¹³ Such choices do not stand alone, as together they shape the course of care a patient receives. The direction and nature of the care which results reflects the practices that are routinely followed by the individual, the team and the

service provider. Whilst providers may hold in their head a firm view of the nature of SPC, the realities of care may, explicitly or implicitly, force them to take a different direction.

Insufficient staffing to manage the caseload at hand results in a pressurised working environment. The NHS services I observed, in particular, faced staffing shortages on a regular basis. Strategies to manage caseloads may include refusing care, delaying care, varying the level of care offered, and discharging from care.³¹⁴ To achieve the desired outcome (such as assigning a category of no need or a delayed need for SPC) and subsequently manage workload pressures, categories of need employed may vary.

Observations of cardiac surgery and neuro-rehabilitation admission conferences show how complex negotiations take place between members of the multidisciplinary team as they 'rule in' or 'rule out' patients with a need for care.⁹¹ Approaches to patient selection varied as a result of staffing mix, the organization of referrals, and attitudes to patient characteristics of a social or moral nature. However, the authors of this work identified two key points in decision-making about need. The first was the existence of implicit rules about which patients should receive care, and the level of care offered. The second was the nature of these rules, which may encompass both moral judgements and organizational criteria.³¹⁵ As staff explored each patient's circumstances and constructed their need for care, they moved between medical and social discourses reflecting, respectively, professional norms and wider societal beliefs. Thus, concepts of 'deservingness' crept in to their decision-making.⁹²

In my observations, implicit rules about need for care centred on the primacy of the physical. The requirement for patients to clear a 'physical needs'

hurdle to gain entry to SPC reduces the number of patients staff may define as eligible for care. In spite of suggestions in documentary policy, patients or carers will not be considered for care on psycho-social grounds alone. This reflects the findings of a study into rationing of access to cancer genetics services.³¹⁶ Here, as a result of negotiations between staff members, previously defined categories of need for care such as inclusion criteria for a service (whether determined locally, regionally or nationally) became fluid. The flexing of these boundaries resulted from workload management pressures, and thresholds for care were set to contain the numbers of patients classified as requiring treatment.

However, SPC provides ongoing support to patients, rather than a one-off procedure such as a surgical intervention or risk assessment. As such, my observations showed that the crucial concern in workload management was less likely to be defining a presence or absence of need, and more likely to focus on assigning a degree of need and subsequent intensity of service offered. It is in this area that the issue of age tentatively appeared.

Age and SPC

I did not observe patient care being withheld as a result of patient age. However, some of my observations suggest older patients may be perceived as less deserving of care (to use Hughes' terminology⁹²). Thus, I observed older patients were more likely to wait for an inpatient bed, young patients were assigned a bed in a private side room rather than a bay if possible, and older patients were considered for discharge to a different service if their diagnosis was unclear, all apparently on the basis of their age.

Glaser and Strauss offered an explanation for the influence of age on medical staff's attitudes and actions towards dying patients, based on a concept they termed 'social loss':

The total of the valued social characteristics which the dying patient embodies indicates the social loss to family, occupation, and society on his death. ³¹⁷

In their work, age was a critical factor on which nurses caring for dying patients calculated a patient's social loss. Older patients were seen as having enjoyed a full life, were currently contributing little to their family or society through employment, and had no future worth. ³¹⁸.

In their study, these implicit judgements resulted in perfunctory medical care with little attention given to the psychological or social needs of dying older patients. ³¹⁸ I am not suggesting this reflects current SPC practice.

However, as David Hughes' work has shown, judgements about patients as a result of dimensions other than strict medical criteria do form a key part of implicit rationing. ⁹⁰ There are glimpses within my data that SPC staff may make an extra effort for 'young' patients – do they regard these deaths as representing a greater social loss, and does this influence their categorisation of need? Decisions may therefore be taken to alter the quality or quantity of SPC as a result of age, but the impact of this on patients may be difficult to determine. ⁹⁰

The importance of context in determining need

We are left, then, with three factors derived from the present study that may influence a move from the 'ideal' to an 'actual' model of need:

1. The skills of available SPC staff (predominantly focused on the physical domain)
2. The number of available SPC staff (leading to workload management by refusing/delaying/reducing SPC, in part through a focus on the acute and the changing (predominantly in the physical domain))
3. Rules of 'deservingness' including a patient's age (leading to refusing/delaying/reducing SPC to reflect levels of deservingness)

The third suggestion is tentative, as whilst this and previous research suggests issues in this area, these are not strongly identifiable throughout all data.

Further, my findings suggest need for SPC is a continuous rather than dichotomous concept. The placement of patients on the continuum of need will vary during the course of their disease. Their position is likely to reflect their own situation and characteristics, and the competencies, availability, attitudes and interaction of SPC staff at each point in time. Classification of need for care will be reflected in the care offered. Thus, definitions of need for care should emphasise the importance of patient/provider interactions, rather than focus on the patient alone. This approach is in a way echoed by the concept of need for health care existing only where that care is effective. Staff provide what they are competent and able to provide, and in so doing shape their normative ideas of need.

Rudolf Klein has argued that debates around access to care must take account of the nature of decision making, and how decisions at different levels relate to each other.³¹⁹ Allocation of resources and the setting of guidelines takes place at the macro level, with policy set at a governmental or regional level. However, it is the day to day decision making of medical

staff at the micro level that determines that actual care that patients receive. As he states: 'we must understand people accomplishing organisation in a multitude of locally situated interactions.'³¹⁹

In seeking to achieve equity, we must therefore consider the relationship between individual decision making and variations in access to care. Explicit guidelines such as those set down by NICE or Government strategy may aim to eradicate inequities in access to SPC. However, such strategies will be ineffective if decisions taken at the micro level enable patient characteristics such as age to determine the nature of the care offered.³²⁰ It is, of course, widely acknowledged that medical staff must draw on their own experience and knowledge to respond to each individual patient's circumstances, rather than simply make decisions as a result of criteria determined at a macro level.³²¹ The relationship between macro and micro is complex, and attempts to ensure fair decision-making at all levels are challenging.³²²

I suggest that the interaction between the macro and micro reflects the nature of the two concepts of SPC depicted here. The first, comprehensive, model of need is the 'explicit' model, reflecting publicly stated and agreed norms about the nature of SPC. The second is the 'implicit' model, revealing the actual nature of the services and the care they are able to offer. A pragmatic concern with 'situated action' requires the observation of dynamic interactions between individual agency and the environment, and consideration of how these contribute to the nature of the phenomenon under observation.²⁹² Drawing on this consideration, and on Eisenberg's and Clark's work on the interactional nature of clinical decision making, I developed a further model to reflect the spheres of influence within which care is determined [Figure 5.7].^{280;323}

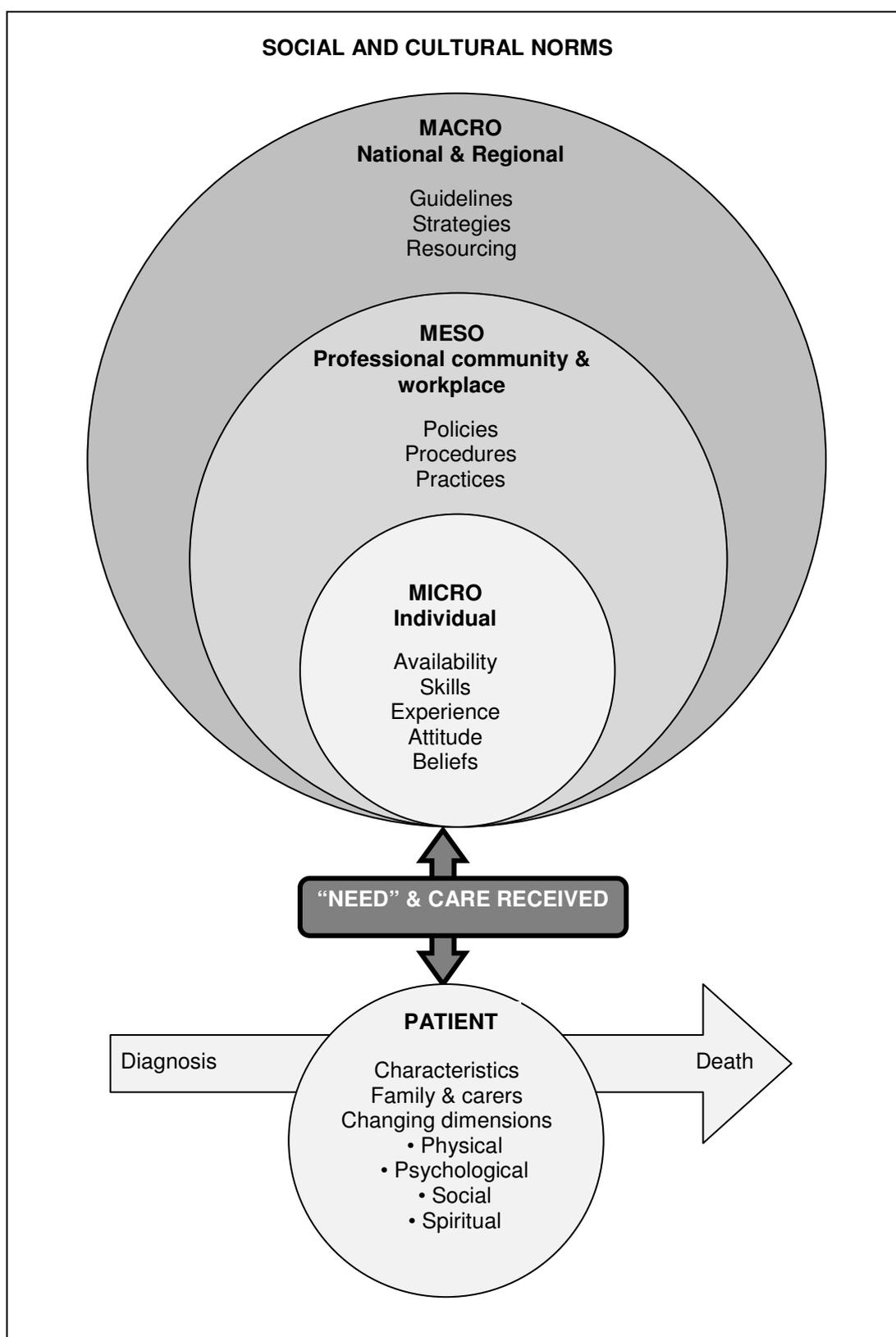


Figure 5.7 A model of the influences on specialist palliative care received

Whilst inevitably reduced to a static and relatively simplistic presentation, this model presents the concept of need as one which reflects an ongoing journey of multiple encounters between the patient and the SPC and wider medical system. Each encounter will add to the previous to determine the overall care pathway the patient follows. This reflects the fluid and contextual nature of the idea of need for SPC. All levels are influential within the subject of my study. Policies including the NICE guidelines on supportive and palliative care set out the parameters of SPC services nationwide.¹⁹ These are subsequently reflected, along with professionally agreed norms of care, in the institutional policies and procedures of SPC providers. However, these are then modified by the pressures of the workplace, including staffing numbers and skill mix, and the attitudes and practices of individual staff members. The interactions of these staff with each other in discussing patients' requirements, and with patients and carers themselves, then determine the model of need for care.

5.6 Conclusions

This study has shown that it is possible to formulate an idea of need for SPC. However, this is unlikely to be static. It is the result of complex interactions between patients and providers, within the context of wider social processes. My work here has shown that the categorization of patients within SPC is unlikely to be one of a dichotomous need/no need, but an ongoing process of variations in the nature of the service offered in the context of limited resources. I feel both models (the aspirational and the actual) are valid and useful. The first summarizes the 'public' face of SPC, and this may be useful at the macro level in population needs assessment and the quantification of those who may benefit from care. Estimates of need at this level may therefore provide evidence of *all* those who could benefit from care in a context of fully developed and resourced SPC services. However, the second

model is a more realistic depiction of working practice and human judgement. Investigations of need at this level reflect the ongoing reality of care, and may present useful evidence on the influence of patient characteristics on the distribution of care.

As outlined previously, data derived from this ethnography were also used to guide my choice of HRQL instrument as a measure of need for care. In the next chapter, I discuss previous approaches to measuring need for SPC, and why, in the absence of high quality SPC needs assessment instruments, existing HRQL questionnaires may provide a suitable alternative approach. I present the methods and results of a systematic review and critical appraisal of HRQL instruments used in lung cancer and palliative care, including how ethnographic data were used to inform an assessment of instrument content validity. Finally, I present detailed summaries of the shortlisted instruments and argue why two of these instruments may be suitable measures of SPC need within the cross-sectional survey of lung cancer patients.

Chapter 6

Measuring need for specialist palliative care: location and critical appraisal of existing instruments

And the arts of measuring and numbering and weighing come to the rescue of the human understanding – there is the beauty of them – and the apparent greater or less, or more or heavier, no longer have the mastery over us, but give way before calculation and measure and weight.

Plato. The Republic of Plato. ³²⁴

To evaluate equity of use of a health care service (whether there is equal use for equal need), need for that service must be measured. The first stage in measuring need is to operationalise it, by setting out a definition of need for care, and the domains this encompasses. Health care services will vary in the domains covered by concepts of need for that service. This is because the domains of need will differ according to the aim of the service, and on the benefits it will confer to the patient. For example, the need for a surgical procedure such as the removal of a suspected malignant melanoma may be determined purely by the presence of a suspicious mole (with an explicit definition of ‘suspicious’). Other factors, such as comorbidities or additional clinical considerations, may not be important in determining which patients will benefit from a biopsy, and which will not. By contrast, as the previous chapter highlighted, initial assessments of need for SPC may consider a diverse range of issues, including the patient’s symptoms, social circumstances, and their family’s anxiety. The definition of ‘need’ for these two services will therefore differ substantially, reflecting the varying domains in which patients will benefit from them.

The second stage in measuring need is to choose a method by which to assess it. The method chosen to measure need will flow from the definition of need being applied, and in particular the domains which this encompasses. To return to our melanoma example, researchers may look to clinical guidelines on the type of moles which should be removed to classify those patients who do, or do not, have a need for a biopsy. Having set out the domains of need (in this case, covering clinical information alone) the decision must be then be made on how to gain information on the nature of the suspicious mole, and whether it meets the guidelines for removal. This could be achieved, for example, through a retrospective audit of medical records of dermatology services. However, with more complex definitions of need for care, such as those applied to SPC, a different approach is required to obtain comprehensive data on the domains of need being measured. For example, it may be that to understand a patient's symptoms, social circumstances and the emotional state of themselves and their family, researchers may wish to gather new data directly from patients, rather than relying on medical records alone.

All measurement of need must be conducted rigorously and systematically. Explicit criteria must be applied to each patient to determine their level of need, and these criteria must be transparent and reliable. This is where the requirements of research and the practice of day-to-day clinical decision making may differ radically. As the previous chapter showed, clinical decisions about a patient's need for care may be based on criteria which differ from official guidelines, and be influenced by factors including the resource context within which practitioners are working. In SPC, explicit 'tick box' lists are on occasion used, but more frequently these are employed to prioritise, rather than decide, need for care within patients, and not always consistently. As far as possible, research requires a thorough and

replicable approach to determining patient need. In situations where this requires the collection of data directly from patients, such data must be obtained using instruments which are psychometrically robust and appropriate for use in the relevant patient groups.

This chapter considers how to measure need for SPC to assess equity of use. It argues that need for SPC may be measured using an existing HRQL instrument. In doing so, it reviews definitions of HRQL and how this may relate to need for health care. The key properties of HRQL instruments are explained and discussed. It then reports on a systematic review and critical appraisal of HRQL instruments used in cancer and palliative care. Finally, it explains the choice of HRQL instruments suitable for use as indicators of need for SPC, based on data derived from the ethnographic study described in the previous chapter.

6.1 Health-related quality of life, need, and specialist palliative care

A number of instruments have been developed specifically to assess palliative care need and outcomes of care, detailed in systematic reviews of the field.³²⁵⁻³²⁷ However, in spite of the prevalence of instruments for use with palliative care populations, two major criticisms have been made of the available options. Firstly, instruments frequently fail to determine and subsequently cover a comprehensive range of domains of need for care, often excluding dimensions such as spirituality.³²⁵ Secondly, instruments have often undergone limited psychometric testing, and their reliability and validity cannot be ascertained.³²⁷

To address such concerns, the Problems and Needs in Palliative Care Questionnaire (PNPC) was developed.³²⁸ Drawing upon interviews with patients and providers to develop a comprehensive model of need for care,

this measure covers activities of daily living; physical symptoms; role activities; financial and administrative issues; social, psychological and spiritual issues; autonomy; information needs; and quality of care. It asks whether items are a problem, and whether professional help is required. A short version has also been developed.³²⁹ Despite reaching reasonable levels of psychometric robustness, however, three concerns arise with this instrument in researching need for care. Firstly, it defines need for care as a wish to receive support for a problem. Thus, it focuses on what I would label demand rather than need. Secondly, it is designed for use as a clinical rather than a research tool. Thirdly, to date all psychometric testing has been undertaken in Dutch, and no English version has been validated.

The PNPC draws heavily on concepts of HRQL in its content.³²⁵ As the widely-used WHO definition of palliative care states, the aim of such services is 'the achievement of the best quality of life for patients [with advanced, progressive illness] and their families.'²⁷ Quality of life is, therefore, a major outcome of palliative care.³³⁰ Considering the dearth of high quality instruments developed specifically to assess palliative care need, I therefore turned to consider the potential link between SPC need and HRQL, and the utility of using an existing HRQL instrument to measure need for care.

Quality of life can be an ambiguous concept. There remains much debate about the meaning of quality of life (QL), and the linked, subsidiary concept of HRQL.³³¹⁻³³⁴ HRQL is acknowledged to be a narrower construct than QL, focusing on the effect of illness and subsequent health care on patients' lives.³³⁵ Whilst it is agreed to be multidimensional in nature, a consensus on a single definition has yet to emerge.³³⁵ Suggested domains of HRQL frequently include physical function, symptoms, global judgements of

health, social well-being, cognitive function, role activities, personal constructs (such as life satisfaction and spirituality) and satisfaction with care.³³⁶ For example, Bowling offers an overall definition of HRQL as;

*...optimum levels of mental, physical, role and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well-being. It should also include some assessment of the patient's level of satisfaction with treatment, outcome and health status and with future prospects.*³³⁷

Definitions of HRQL differ further according to the context and the population of interest. So, for example, in comparison to generic or other treatment areas, there is a greater emphasis on existential issues as central to HRQL in palliative care.³³⁸ One definition for HRQL in palliative care which has been suggested is:

*QL in the context of advanced, progressive, incurable illness, is defined as the subjective experience of an individual living with the interpersonal, psychological, and existential or spiritual challenges, that accompany the process of physical and functional decline and the knowledge of impending demise. A person's QL can range from suffering, associated with physical distress and/or a sense of impending disintegration, to the experience of wellness and personal growth arising from the completion of developmental work and the mastery of developmental landmarks.*³³⁹

An association between HRQL and need for health care can only be made when the domains of HRQL are similar to the proposed domains of need for a service. This would not be the case for our suspected malignant melanoma, where clinical factors alone (the presence of a suspicious mole) may be enough to trigger an agreed need for a biopsy. Such a patient's quality of life, although likely to be affected by their concern over the suspicion of skin cancer, may not be judged as relevant to their need for care. By contrast, need for SPC is multi-dimensional, encompassing physical symptoms, functional issues, psychological issues, and a patient's social situation. These

identified domains of need tie in with definitions of HRQL in palliative care, covering as they do physical comfort, psychological wellbeing, social functioning and wellbeing, spiritual wellbeing and meaningfulness of life, physical functioning, cognitive functioning, overall perceived quality of life and quality of dying of patient.^{340 341} It may be possible, therefore, to consider HRQL as an indicator of need for SPC.

HRQL has already been used to approximate patients' need for healthcare where validated health care needs questionnaires are not available.^{342;343} In taking such an approach, researchers can draw on an abundance of existing, psychometrically robust HRQL instruments. The use of existing instruments is recommended wherever suitable, as the development of new measures is a lengthy undertaking guided by strict procedures.³⁴⁴ However, HRQL instruments are based on their author's own definitions of HRQL.

Definitions of HRQL within palliative care frequently follow the standards and scope set out for providing palliative care; again, an indication of the close ties between the aim of the service, need for the service, and measures of HRQL.^{345;346} Yet these definitions do vary, and it is not possible to assume that any HRQL instrument developed for use with palliative care populations will closely match SPC provider's concepts of need for their services.

There is a further consideration in using HRQL instruments to indicate need for a health care service. Within clinical practice, decisions on need are most frequently taken by health care professionals, rather than patients. Patients' perceived need may be expressed as demand for a service, but it remains the case that need is usually professionally-defined. HRQL instruments, by contrast, are now routinely completed by patients, rather than observers. This follows a number of studies showing that doctors and patients give

widely differing reports of HRQL following treatment.³⁴⁷⁻³⁴⁹ Within palliative care, it is still argued that proxy ratings of HRQL (given, by example, by close family or friends) may be necessary when a patient is too ill or frail to complete an instrument themselves.³⁵⁰ However, the first choice of respondent remains the patient. In using HRQL instruments as an indicator of need for care discrepancies may, therefore, arise between the professional's perceptions of need, and the patient's rating of their HRQL.

Ideally, of course, need for health care should be measured using an instrument designed specifically for that purpose. However, when need and HRQL are closely aligned (as they are within SPC) the use of an existing HRQL instrument may prove an effective way of obtaining valid and reliable data on need for care. Caution must, however, be exercised in choosing an appropriate HRQL instrument as an indicator of need for care. The author's underlying constructs in developing the instrument, the psychometric properties it has, and its appropriateness for use in the intended population must all be considered. Fundamentally, the content of the HRQL instrument must be checked against the operationalised definition of need for that service which is being measured. The following section considers in detail the different types of HRQL instrument which are available, and the properties they must have to demonstrate robustness for use.

6.2 Properties of health-related quality of life instruments

HRQL instruments may be generic, disease or domain specific. Generic instruments are developed to be applicable across all respondents, to enable comparisons between healthy and ill adults, or between adults with different illnesses. Their utility is in the ability to compare HRQL scores across many different patient and non-patient groups, and for this reason they lend themselves well to cost-effectiveness studies. Disease-specific instruments

are more sensitive, as they are able to include items relevant to the diagnosis of study, but they preclude the comparison of HRQL scores between different disease groups. Many clinical trials use both a generic and disease-specific instrument for these reasons.³³⁷ Domain-specific instruments do not measure HRQL, but only one or more dimensions of this (for example, physical symptoms or functional status), although they are frequently used as proxies for global HRQL.

HRQL instruments must undergo extensive development and testing to ensure they meet adequate levels of reliability, validity, responsiveness, and acceptability. Guidelines have been published for the evaluation of the psychometric properties of instruments.^{336,337,351} These are briefly summarised below.

Conceptual and measurement model

All HRQL instruments should be based on a clear conceptual model of HRQL, stating the domains this is envisaged to encompass. The theoretical basis and methods used for developing the instrument's content should be stated, as should the involvement of the target population in the development process. Measurement scales should measure a single distinct domain with sufficient variability of responses. This is to ensure that different scales within an instrument are measuring the stated domain of interest, and nothing else, and that the given response options are appropriate both to this item/domain of interest and to the target population. Additionally, the scale scoring system used should be clearly justified, with instrument authors explaining the rationale and methods for obtaining scale scores from raw scores, and for any transformations that are applied. This is essential if scale scores are to be meaningful and standardised across all users of an instrument.

Reliability

The reliability of a HRQL instrument is the degree to which it is free from random error. The two major aspects of reliability to be evaluated are internal consistency and reproducibility (test-retest).

A. Internal consistency

Internal consistency tests whether items in a scale are measuring the same concept. It reflects two aspects: the number of items in a scale, and the average correlation between these items.³⁵² Internal consistency is often tested for both the entire instrument, and the domains or sub-scales which make up the instrument, using the Cronbach's alpha coefficient. The accepted standard is a coefficient of 0.70 or above, although higher figures are required if HRQL is being assessed on an individual, rather than a group, level. Low alpha scores indicate that the scale either has an insufficient number of items, or the items within the scale are not measuring a cohesive construct.

B. Test-retest reliability

Test-retest reliability is evaluated in respondents who are assumed not to have changed on the HRQL dimension of interest, and examines whether their scores remain stable over time as expected. It is assessed using either the Pearson or the intraclass correlation coefficients (ICC), with a minimum of 0.70 being deemed acceptable.

Validity

The validity of a HRQL instrument is the degree to which it measures what it claims to measure. There are three main ways of assessing validity – content validity, criterion-related validity, and construct validity.

A. Content validity

Content validity is focused on whether an instrument covers all the relevant aspects of the construct it is claiming to measure. It is not possible to assess content validity statistically. Instead, the content of an instrument should be examined and adjusted in light of interviews with potential respondents, expert review, comparison to existing instruments, review of the literature, and pilot testing of draft versions.

B. Criterion-related validity

Criterion-related validity is the degree to which a HRQL instrument correlates with a criterion (gold-standard) measure. As criterion measures are not to be found easily in HRQL, this aspect of validity is rarely assessed.

C. Construct validity

Construct validity requires that the proposed interpretation of a measure's scores is drawn from a theoretical underpinning of the constructs which are being measured. It is evaluated by testing hypotheses about how an instrument should 'behave' and about the expected relationships between the instrument and other variables or measures of the same construct. There is no single test for construct validity, and evidence for instruments is often gathered over a period of time and repeated use. There are a number of different aspects of construct validity, and it can be assessed internally, within the instrument, and externally, by comparison to other instruments. Internal and external construct validity are explained briefly below.

Internal construct validity

Internal consistency is assessed by determining that sub-scales are homogenous and valid. Scale inter-correlation is used to consider whether sub-scales are measuring separate, but related, constructs. Factor analysis

can be used to explore the scaling structure used within an instrument – for example, to ensure that items are grouped as they should be. Known groups testing investigates whether scale or instrument scores vary as expected between respondents, when grouped by a characteristic also measured by the instrument. For example, do patients with a poorer reported global quality of life also have poorer scores in the symptom domain?

External construct validity

Convergent validity considers whether an instrument or sub-scales correlate as predicted with other measures, usually alternative HRQL instruments.

Divergent validity is the opposite – whether an instrument or sub-scales correlate poorly as hypothesised with other measures. Known groups testing can also be conducted by comparing score differences between groups of respondents classified by an alternative, external measure. For example, do patients with poor performance status as measured by an alternative instrument also report greater symptom burden on the instrument being assessed?

Additional properties

Responsiveness

Responsiveness refers to the degree to which an instrument is able to detect change over time. Whilst there is no one established method with which to assess responsiveness, the general principle is to calculate a measure of the magnitude of change in reported HRQL over a set period of time or after a specific event (such as treatment).

Interpretability

Interpretability refers to the ability to assign qualitative meaning to an instrument's quantitative scores. This may be facilitated, for example, by the use of population 'norm' scores for the instrument, or the comparison of scores to particular clinical conditions, known treatment needs or life events.

Acceptability

The degree to which an instrument places demands on respondents, and administrators, is an important aspect of an instrument's suitability for use in its target populations. Respondent burden considers the time and effort required by patients to complete an instrument, and the impact completing the instrument may have on them. The ease of reading and length of the instrument should be suitable for the intended respondents and setting of administration. Respondent burden can be assessed by considering time to completion, but also indicators such as percentage completion rates, non-response by item, and how responses are distributed across items and domains. Administrator burden considers the requirements of administering and scoring the instrument, and guidance should be provided by instrument developers for researchers on these points.

Practical considerations (appropriateness)

In addition to the psychometric aspects of instrument development and testing summarised above, a key aspect in evaluating and choosing between HRQL instruments is their appropriateness for the planned research study.

Aspects to be considered include:

A. Conceptual relevance

Perhaps the most fundamental consideration in the choice of an instrument is the relevance of their content to the planned study. For example, if a

particular outcome of interest is pain, does the instrument cover this in sufficient depth? Are items included which are irrelevant? And are items excluded which are relevant?

B. Mode of administration

Has the instrument been developed and validated to be administered in a face-to-face interview or by telephone, or to be completed by a patient in a clinic or at home after receiving it in the post? Psychometric properties must have been evaluated for each different mode of administration.

C. Relevance to study population

Is the instrument appropriate for the intended study population? Has it been validated in respondents of the correct age, diagnosis, and social situation? What assessment point has it been developed to cover – for example, was it developed for newly diagnosed cancer patients and has not been validated in advanced cancer patients? If study participants are predominantly older and retired, does the instrument include irrelevant or unsuitable questions about employment?

Choosing a HRQL instrument

The choice of a HRQL instrument must be guided by both psychometric and practical considerations, as outlined above. Importantly, instruments should meet basic criteria of validity and reliability. It is unlikely that a 'perfect' match will be found between an existing instrument and the aims, objectives and planned conduct of a study. Therefore, the final choice of instrument may involve a trade-off between psychometric standards, appropriateness and feasibility.³³⁶ The process of finding and appraising a suitable instrument is outlined in the following section.

6.3 Systematic search for and critical appraisal of HRQL instruments

To ensure all HRQL instruments which may be suitable for use in a study are located, a systematic search must be undertaken. The approach I took to identify HRQL instruments used in the fields of lung cancer and palliative care is outlined below. I also discuss the results of a critical appraisal of instruments for their psychometric robustness and appropriateness for use as an indicator of need for SPC.

Aim and overview of methods

My aim in this strand of work was to systematically identify and appraise critically HRQL instruments suitable for use in adult lung cancer and palliative care patient populations in the UK. I would then select an instrument based on psychometric properties and appropriateness of both content and administration to use as an indicator of need for SPC in the cross-sectional survey of lung cancer patients.

I located HRQL instruments through a literature review using bibliographic databases, library catalogues, internet searching and discussion with experts in the field. My subsequent critical appraisal of these instruments was based on published guidelines and results from my ethnographic study. An overview of the process is given in Figure 6.1, and explained in more detail below.

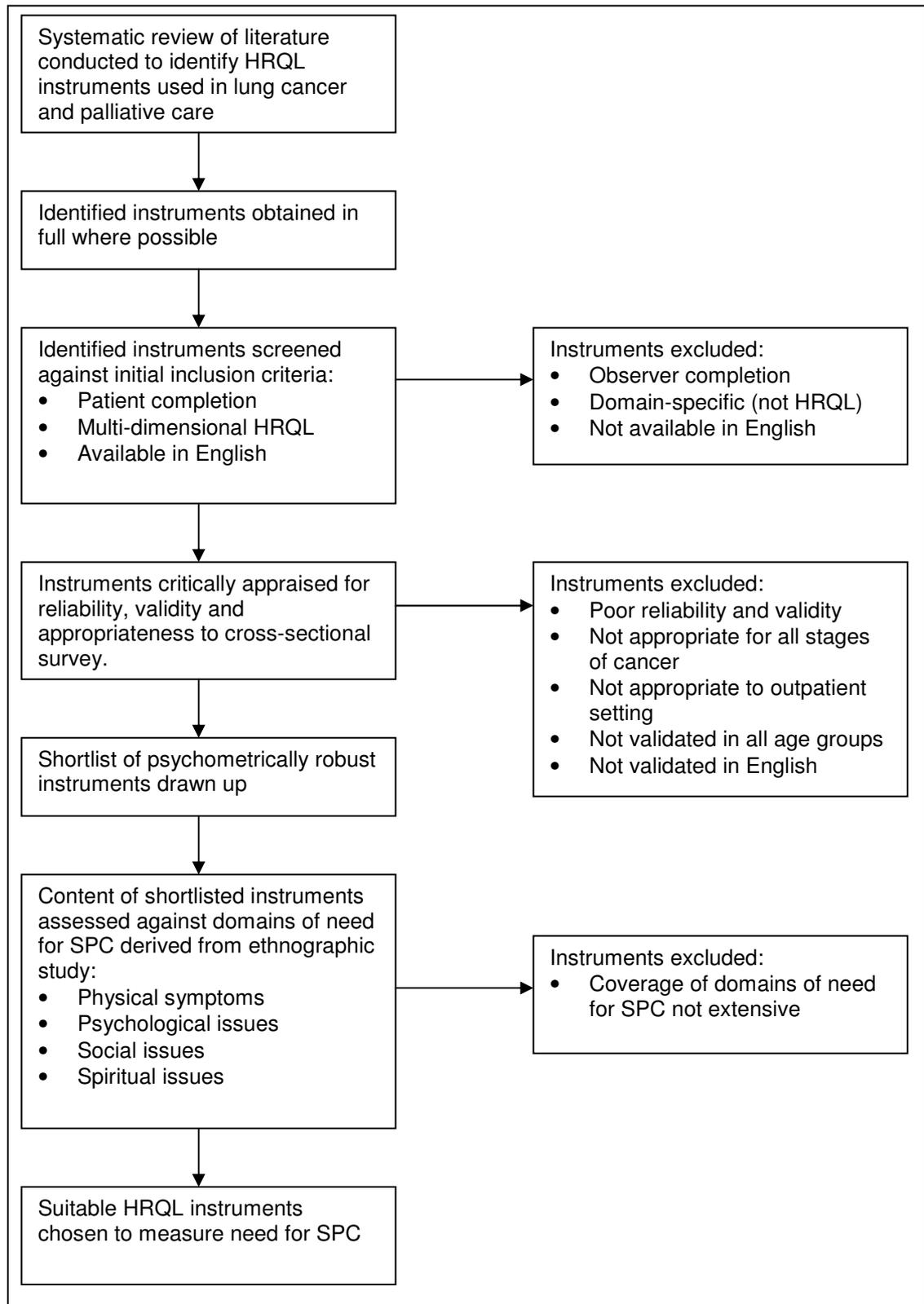


Figure 6.1 Methods of review and critical appraisal of HRQL instruments

Search strategy

I employed four strategies of searching.

Firstly, I undertook a systematic search of bibliographic databases for studies published from 1966 (the earliest database listing) to the present. I conducted searches in Medline (Silverplatter, 1966 onwards), Embase (Ovid, 1980 onwards), HMIC (Silverplatter, 1979 onwards) and SIGLE (Silverplatter, 1979 onwards). I used a combination of text words and thesaurus terms for three major search concepts and their synonyms: quality of life, palliative care, and lung cancer. I developed the search strategy in Medline and adapted this for other databases [Table 6.1]. I carried out an initial search in December 2004, and repeated this in September 2005. All papers identified from each database search were imported into reference management software (EndNote v 6.0) and duplicate references deleted. I then scrutinised all identified citations against the inclusion and exclusion criteria (reported below) to determine whether the full paper should be obtained. I also examined bibliographies of full-text articles identified through database searching and meeting the initial inclusion criteria for further relevant studies.

Table 6.1 Example search – Medline
1. quality of life [tw]
2. "quality of life" [MeSH]
3. #1 or #2
4. palliative* [tw]
5. hospice* [tw]
6. end of life [tw]
7. terminal care [tw]
8. supportive care [tw]
9. "palliative care" [MeSH]
10. "terminal care" [MeSH]
11. "hospice care" [MeSH]
12. #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11
13. lung cancer* [tw]
14. lung neoplasm* [tw]
15. lung tumour* [tw]
16. lung tumor* [tw]
17. lung carcinoma* [tw]
18. "Lung Neoplasms" [MeSH]
19. #13 or #14 or #15 or #16 or #17 or #18
20. #12 or #19
21. #3 and #20
22. #21 limited to English

Secondly, I used a library catalogue search, covering LSHTM, UCL and the British Library, to identify major relevant textbooks covering HRQL measures. Instruments identified through the text book search which had previously been used in palliative care or lung cancer patients were included in the review.

Thirdly, I searched relevant internet websites for unpublished research in this field and further details on existing HRQL instruments: the Mapi Research Institute (www.mapi-research.fr) and their subsidiary site the Patient-Reported Outcome and Quality of Life Instruments Database (Proqolid: www.proqolid.org), the American Thoracic Society Quality of Life Resource (www.atsqol.org/) and TIME (Toolkit of Instruments to Measure

End of Life Care: www.chcr.brown.edu/pcoc/toolkit.htm). Additionally, I entered the titles of all instruments located through the above three methods of searching into Medline, Embase and Google to identify any additional papers or information describing their development or use.

Finally, I consulted with experts in the field of lung cancer, palliative care and quality of life for further recommendations on relevant instruments.

Inclusion and exclusion criteria for papers

To be included within the review, papers had to meet at least one of the following criteria:

- Containing information about the development, adaptation and/or psychometric properties of HRQL instrument/s for use with adult palliative care or lung cancer patients.
- Describing the validation of existing HRQL instrument/s for use with adult palliative care or lung cancer patients in different settings or populations
- Comparing the performance of existing HRQL instruments for use with adult palliative care or lung cancer patients.

I excluded studies using HRQL instruments as process or outcome measures, such as clinical RCTs. Studies and reviews published in English in peer reviewed journals or grey literature were eligible for inclusion.

Inclusion and exclusion criteria for HRQL instruments

I obtained, where possible, the full text of all instruments identified through the papers located in the literature search. Generic, cancer, lung-cancer, and palliative-care specific instruments were all eligible for inclusion, if they had

been used in lung cancer or palliative care populations. Instruments were subject to an initial brief assessment and exclusion criteria applied.

Instruments were only taken forward for full critical appraisal if they were:

- Designed for completion by the patient (either self-administered or interviewer-administered), rather than observer-rated.
- Designed to make a comprehensive assessment of multiple domains of HRQL (physical, emotional and social well being, and functional ability), rather than one domain only (such as physical symptoms).
- Available for use in the English language.

Critical appraisal of HRQL instruments

HRQL instruments meeting the initial inclusion criteria (patient-rated, covering multidimensional HRQL and available for use in English) were subject to a critical appraisal of their psychometric properties, and appropriateness for the cross-sectional survey of lung cancer patients.

I abstracted data on the psychometric properties of the HRQL instruments into a standardised critical appraisal form developed for this study, one form per instrument. As some HRQL instruments were identified and described across a number of different articles and books, forms therefore could contain data from a variety of sources.

The form enabled me to summarise the key psychometric characteristics of each instrument: its reliability (internal consistency and reproducibility), validity (content and construct), and responsiveness [Table 6.2]. I noted further information on the instrument's conceptual and measurement model, interpretability and burden. Finally, I abstracted descriptive information: the number of items, the domains covered, the mode of administration

(interview or self-complete), the patient groups tested in (including age), the setting tested in, and the languages validated in, to further assist in decisions about the appropriateness of each instrument for the planned study setting.

Table 6.2 Critical appraisal of HRQL instruments: key points		
1	Conceptual and measurement model	What is the conceptual basis of the instrument? What is the measurement model used – does it include tests of scaling assumptions and floor and ceiling effects of items?
2	Reliability	Is the instrument is free from random error?
	a) Internal consistency	Do items in the scale measure the same concept?
	b) Reproducibility (test-retest and inter-rater)	Test-retest: to what degree does the instrument reproduce stable scores over time in respondents who are assumed not to have changes on the domain being assessed?
3	Validity	Does the instrument measure what it claims to measure?
	a) Content	Is the instrument comprehensive, without excluding any major areas deemed to be relevant?
	b) Construct	What hypotheses are given about how the instrument 'behaves' and what the expected relationships between the instrument and other measures of the same construct are?
4	Responsiveness	Is the instrument able to detect clinically significant change over time?
5	Interpretability	Can meaning be assigned to the quantitative scores derived from an instrument?
6	Burden	What is expected of the participant (respondent burden) in completing the form? What are the time implications for the researcher in e.g. scaling the responses? (administrator burden).
7	Appropriateness to this study	What patient groups and settings has the instrument been tested in? Is it culturally applicable? What is the method of administration?

Content assessment of shortlisted HRQL instruments

Following the first phase of critical appraisal, I drew up a short list of instruments based on the following criteria:

1. Good reliability and validity
2. Appropriate for use at all stages of cancer, including the recently diagnosed and those with advanced disease
3. Comprehensive coverage of physical, psychological and social dimensions of HRQL

4. Suitable for use in the outpatient setting
5. Validated in English
6. Validated in all age groups

I then undertook a detailed assessment of the content of the shortlisted instruments. Items included within each instrument were compared against the domains of need for SPC derived through my content analysis of qualitative data conducted for this purpose. The methods used to derive these domains were outlined in Chapter 5. Briefly, I developed an initial coding framework from documentary evidence, particularly prioritization scoring systems and assessment tools reflecting potential dimensions of need for SPC. I then applied this to transcripts of home care team and inpatient admissions meetings from RS1 to generate counts of the number of occasions on which these terms or concepts were used. From this, I derived a framework covering the specific dimensions of need discussed and used by providers in assessing patients referred to their services [Table 6.3].

Table 6.3 Framework for domains of need used to assess HRQL instruments		
Pain	Diarrhoea	Low mood
Breathlessness	Confusion	Patient not coping
Nausea/vomiting	Drowsiness	Thoughts of dying
Weakness	Incontinence	Sleeping problems
Fatigue	Urinary problems	Body image concerns
Anorexia	Dry/sore mouth	Deteriorating condition
Weight loss	Cough	Lives alone
Ascites	Mobility difficulties	Financial issues/concerns
Oedema	Patient anxiety/distress	Relationships with others
Constipation	Depression	Carer anxiety and distress

This framework is thus closely aligned to the ‘aspirational’ model of need I observed, rather than the narrower ‘actual’ model of need, as it was the aspirational model that was typically used to assess new referrals to the service and thus consider initial need for SPC. Additionally, this framework is derived from the detailed content of SPC providers’ discussions. So, instead of reference to an over-arching physical domain of care, the framework covers the specific symptoms SPC staff highlighted. It therefore contains all aspects of a patient’s needs addressed by staff in their first assessment. Having derived this framework, I used it to assess the relevance of each instrument’s content to provider’s conceptualisation of need for SPC. Additional items included within the instrument which were not part of the major dimensions of need for SPC were also assessed for their potential relevance to the target population.

I also studied further important aspects of the short listed instruments. These included the conceptual model of HRQL on which they were based (if stated), and the scoring system used and its justification. The statement of a precise concept of HRQL on which an instrument is based is an important indicator of instrument quality and rigour.³⁵¹ Additionally, a consideration of the scoring system of each instrument was required to investigate how

each might be used as an indicator of need for SPC within a multivariable regression analysis.

Following this assessment, and based on the outcome of all stages of appraisal, I decided which instruments were suitable to use as an indicator of patient need for SPC.

Results

Number of articles and instruments

Bibliographic database searches returned a total of 9832 citations. Following deletion of duplicate references (n = 2254), I screened 7578 titles and abstracts against the inclusion and exclusion criteria [Figure 6.2]. Citations were primarily excluded as they reported the results of studies which had used HRQL instruments as process or outcome measures, with no description of their psychometric properties. 148 publications were retrieved in full text for further scrutiny.

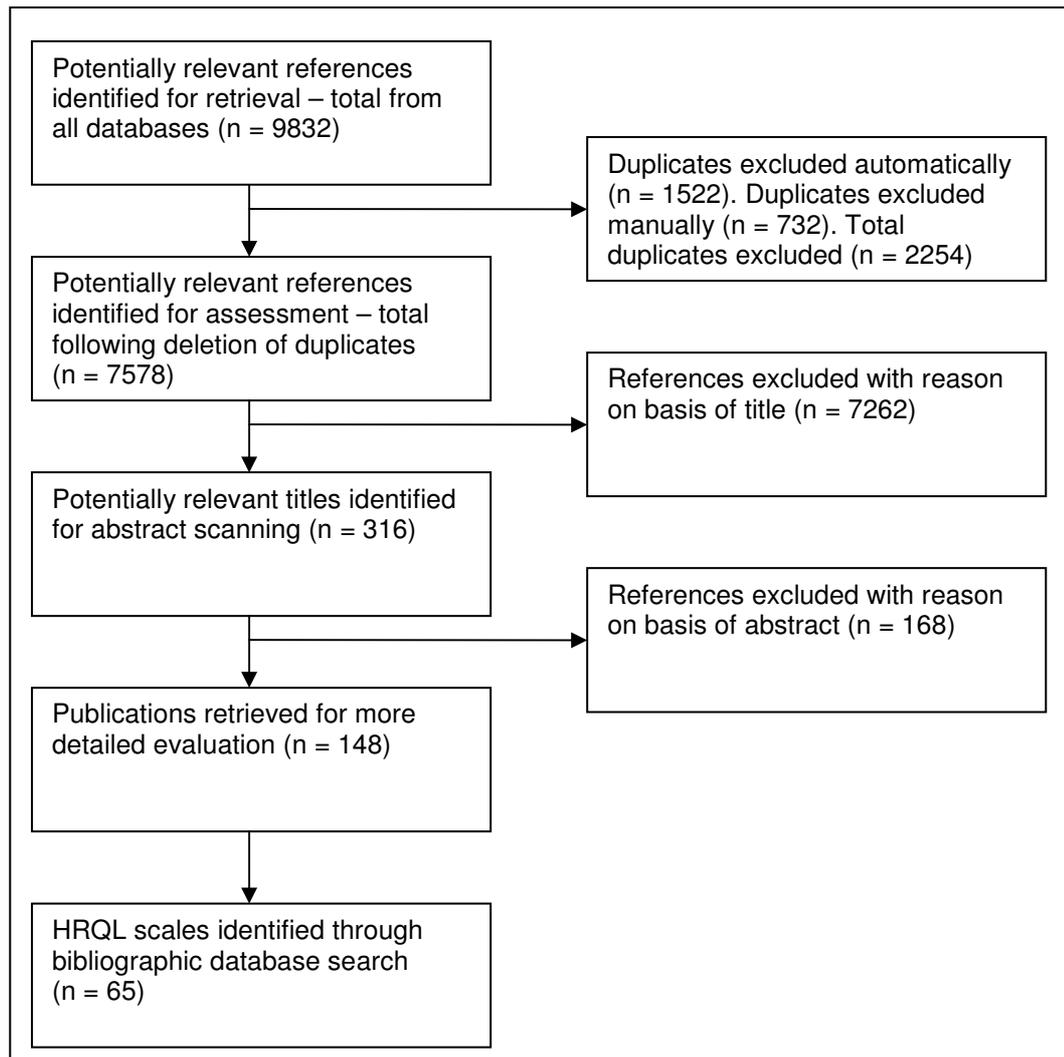


Figure 6.2 Flow chart of systematic search

Scrutiny of the full text articles and their bibliographies led to the location of 65 HRQL instruments suitable for use in lung cancer or palliative care populations. Following-up cited references was a particularly effective method of locating the original validation study for many instruments. I identified an additional two HRQL instruments through the manual text book search, and one more through expert recommendation, leading to a total of 68 instruments identified for appraisal.

Initial brief assessment

Following assessment of the identified HRQL instruments against the initial inclusion criteria (patient-rated; multi-dimensional in scope; and validated in the English language), I excluded 31 instruments from further appraisal [Table 6.4]. The largest category of exclusion (n = 22) was for instruments that did not cover multiple domains of HRQL. Instead, these were designed to capture a patient's experience in only one area of HRQL, such as symptoms, functional status or existential issues. Seven instruments were designed to be completed by an observer based on their own judgements of the patient, rather than the patient's own report. One instrument was only available in German and had not been translated to English.

Table 6.4 HRQL instruments excluded from critical appraisal
Not multi-dimensional HRQL
Canberra Symptom scorecard ³⁵³
Cancer Patient Need Questionnaire ³⁵⁴
Cancer Patient Need Survey ³⁵⁵
Client Generated Index ³⁵⁶
Condensed Memorial Symptom Assessment Scale ³⁵⁷
Daily Diary Card ³⁵⁸
Demoralization Scale ³⁵⁹
Edmonton Functional Assessment Tool ³⁶⁰
Edmonton Symptom Assessment Scale ^{361;362}
Herth Hope Index ³⁶³
Home Care Study – Patient Form ³⁶⁴
Hospice Care Performance Inventory – HCPI ³⁶⁵
Karnofsky Performance Status Scale – KPS ³⁶⁶
Life Closure Scale ^{367;368}
Life Evaluation Questionnaire – LEQ ³⁶⁹
Meaning in Life Scale (ML) ³⁷⁰
Memorial Symptom Assessment Scale – MSAS ³⁷¹
Mini-Mental State Questionnaire ³⁷²
Need Satisfaction Scale ³⁷³
Patient Information Survey ³⁷⁴
Quality of End of life care and Satisfaction with Treatment - QUEST ³⁷⁵
Symptom Distress Scale – SDS ^{376;377}
Observer-rated
Hebrew Rehabilitation Center for Aged QL (HRCA-QL) ³⁷⁸
INTERMED ³⁷⁹
Oncology Clinic Patient Checklist ³⁸⁰
Palliative Care Assessment – PACA ³⁸¹
Resident Assessment Instrument for Palliative Care (RAI-PC). ³⁸²
Spitzer Quality of Life Index ³⁸³
Support Team Assessment Schedule – STAS ³⁸⁴
Not available in English
SELT-M ³⁸⁵

Full critical appraisal

38 instruments therefore remained for full critical appraisal. These were divided into four categories – generic (9 instruments), cancer-specific (10 instruments), lung-cancer specific (3 instruments) and palliative care specific (16 instruments), to reflect their different origins and application. Of the 38

instruments identified, just under half (n=17, 44.7%) had been rigorously psychometrically evaluated on all dimensions of reliability (internal consistency and reproducibility) and validity (content and construct). 12 (31.6%) had been tested for their responsiveness (ability to detect change over time). The instruments varied widely in their length (range of 6 to 139 items) and the domains covered. This in part reflected the original purpose of their development, with shorter instruments designed to be used in palliative care populations. However, a number of instruments also had both long and short versions to address concerns of respondent burden in less healthy populations, such as those with advanced cancer.

As a result of the critical appraisal, I shortlisted 6 of the 38 instruments for detailed consideration for use as an indicator of need. Brief details of the 32 instruments excluded at this stage are given in Table 6.5, and in the commentary below. A detailed description of these instruments, including a full account of their psychometric properties (reliability, validity and responsiveness) and appropriateness for the purpose of this study is in Appendix III, page 396.

Table 6.5 HRQL instruments critically appraised but not shortlisted	
Name of instrument	Reason for exclusion
Generic instruments used in lung cancer or palliative care	
EQ-5D ³⁸⁶	5 items. Limited coverage of HRQL dimensions; response options limited.
Fox Simple Quality of Life Scale ³⁸⁷	25 items. No data on reproducibility and responsiveness published. Still in development.
NHP (Nottingham Health Profile) ³⁸⁸	38 items. Evidence of conflation of pain and mobility domains.
SEIQoL (Schedule for the Evaluation of Individual Quality of Life) ^{389;390}	5 domains. Interviewer administered; acceptability in palliative care disputed.
SEIQoL-DW (Schedule for the Evaluation of Individual Quality of Life – direct Weighting) ^{389;390}	As above.
SF-36 (Short Form 36)	36 items. Limited coverage of symptoms.
SIP (Sickness Impact Profile) ³⁹¹	136 items. Psychometric properties in cancer uncertain.
WHOQOL-100 ^{392;393}	100 items. Acceptability in advanced cancer unknown.
WHOQOL-Bref ³⁹⁴	26 items. Acceptability in advanced cancer unknown.
Cancer-specific instruments used in lung cancer or palliative care	
Care notebook ³⁹⁵	24 items. Not psychometrically tested in English.
CARES (Cancer Rehabilitation Evaluation System) ³⁹⁶	139 items. Acceptability in advanced cancer disputed.
CARES-SF (Cancer Rehabilitation Evaluation System –Short Form) ³⁹⁷	59 items. Acceptability in advanced cancer disputed.
QOL-CS (Quality of Life Instrument – Cancer Survivor Version) ^{398;399}	41 items. Not suited to advanced cancer patients.
QLI-C-FP (Ferrans and Power Quality of Life Index – Cancer version) ^{400;401}	66 items. Acceptability in advanced cancer unknown.
FLIC (Functional Living Index – Cancer) ⁴⁰²	22 items. Reported poor acceptability with lung cancer patients.
Quick-FLIC ⁴⁰³	11 items. Reported poor acceptability with lung cancer patients.
Padilla's Quality of Life Index	14 items. Not tested in advanced cancer.
Rotterdam Symptom Checklist ⁴⁰⁴	38 items. Limited coverage of HRQL dimensions; focus on symptoms.
Lung cancer specific instruments	
LCSS (Lung Cancer Symptom Scale) ⁴⁰⁵⁻⁴⁰⁷	9 items. Limited coverage of HRQL dimensions.
Palliative care specific instruments	
AQEL (Assessment of Quality of Life at the End	19 items. Psychometric properties poor.

of Life Instrument) ⁴⁰⁸	
Brief Hospice Inventory ⁴⁰⁹	17 items. Specific to patients receiving palliative care.
EORTC QLQ-C15-PAL ⁴¹⁰	15 items. Still in development.
HQLI (Hospice Quality of Life Index) ^{411;412}	28 items. Specific to patients receiving palliative care.
Initial Assessment of Suffering in Terminal Illness ⁴¹³	20 items. Still in development.
Missoula-VITAS Quality of Life index ³³⁹	26 items. Only suitable for patients with advanced disease.
POS (Palliative Care Outcome Scale) ⁴¹⁴	10 items. Limited coverage of HRQL dimensions.
PQLI (Palliative Care Quality of Life Instrument) ⁴¹⁵	28 items. Not psychometrically tested in English.
Patient Evaluated Problem Score ⁴¹⁶	Unlimited list. Not psychometrically tested.
PNPC (Problems and Needs in Palliative Care) ³²⁸	138 items. Not psychometrically tested in English.
QUAL-E (Quality of life at the End of Life) ^{417;418}	31 items. Interviewer administered.
Supportive Care Needs Survey ⁴¹⁹	61 items. Not used in UK populations.
Therapy Impact Questionnaire ⁴²⁰	36 items. Not psychometrically tested in English.

A. Generic instruments

Whilst some of the generic instruments reviewed were extensively used within cancer research, particularly the SF-36, there were a number of limitations to their use as an indicator of need for palliative care. Firstly, their ability to discriminate between lung cancer patients with and without a need for SPC is likely to be low; few include symptoms other than pain and few have fine enough response formats to generate a range of responses in this group. Secondly, despite their use in lung cancer trials, the inclusion of domains such as work or the ability to walk long distances is redundant when applied in advanced disease. Thirdly, few include domains specific to the assessment of need for SPC, such as existential issues including concepts self, death and dying, and meaning of life. For these reasons, none were short listed for further consideration.

B. Cancer-specific instruments

Many cancer-specific instruments, such as the CARES, the QOL-CS and Padilla's Quality of Life Index, have not proved suitable for administration in advanced cancer patients, limiting their utility in a cross-sectional survey of all stages of disease. The FLIC and Rotterdam Symptom Checklist excluded a number of important dimensions of HRQL, particularly psychosocial items. Finally, the Care Notebook has not been psychometrically tested in English speaking populations and is thus unsuitable for use until its validity and reliability have been confirmed in this language.

C. Lung-cancer specific instruments

The LCSS, whilst it has shown good reliability and validity, is limited in its coverage of non-physical concerns. It additionally relies on being interviewer-administered; for these reasons it was not suitable to use in the planned cross-sectional survey.

D. Palliative-care specific instruments

The largest group of instruments I identified were developed for use specifically in palliative care populations. However, this group also showed the greatest variation in the extent to which instruments had been psychometrically tested, with some showing little or no evidence of their reliability and validity. Additionally, instruments developed for use in palliative care populations varied widely in their content. A number – such as the Missoula-Vitas QLI and the Hospice Quality of Life Index – include items very specific to patients with a terminal illness, and are therefore unlikely to be suitable for use in patients in earlier stages of cancer.

6.4 Short listing and selection of HRQL instrument as indicator of need for SPC

As a result of the critical appraisal, I short listed six potential instruments for more detailed consideration. These were:

1. EORTC QLQ-C30
2. EORTC QLQ-LC13
3. FACT-L
4. McGill Quality of Life Questionnaire
5. McGill Quality of Life Questionnaire – Cardiff short form
6. McMaster Quality of Life Instrument

Details of the psychometric properties of these instruments are given in Table 6.6. The domains of need for SPC that I derived from my ethnographic data encompassed physical symptoms, functional issues, psychological issues, social situation, spiritual concerns, and change over time. To assess how comprehensively each short listed HRQL instrument covered these domains, instrument items were tabulated against identified domains of need [Table 6.7]. The results of the content appraisal of each instrument, along with full details of their characteristics and applicability, are discussed in detail below for each instrument in turn.

Table 6.6. Psychometric qualities of shortlisted HRQL instruments												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
EORTC QLQ-C30 ⁴²¹	30 items; five functional scales (physical, role, cognitive, emotional and social), three symptom scales (fatigue, pain, and nausea & vomiting); plus global QL scale and additional symptom items	Patient completion	Four- and seven-point categorical scales	Domains Cronbach's α .52 to .89 ⁴²¹	-	Literature . Interview s. Expert review. Pilot test.	Divergent validity: scales distinct. Discriminant validity: able to distinguish between patients with different performance status	Scores changed pre- and post-treatment	Time: 11 minutes. Acceptability: 10% patients found one or more items confusing	Inpatient Outpatient Community	Cancer patients, all stages. Age range 36 to 89	English
EORTC QLQ-LC13 ⁴²²	13 items; Lung-cancer related symptoms and treatment side-effects. Supplement to EORTC QLQ-C30	Patient completion	Four-point categorical scale	Domains α dyspnoea subscale .83; pain .54	-	Literature . Expert review.	Discriminant validity: symptom scores related to performance status. scale of instrument distinguished between patients with differing performance status	Scores changed in expected direction during treatment.	Time not known. Acceptability not known.	Outpatient.	Patients with non-resectable lung cancer. Age range not known.	English and other languages.

Table 6.6. Psychometric qualities of shortlisted HRQL instruments												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
FACT-L ⁴²³	44 items; 5 domains plus 'additional concerns': physical well-being, social/family well-being, relationship with doctor, emotional well-being, functional well-being.	Patient completion	Five-point categorical scale	Domains Cronbach's α .53 to 0.89. Lung cancer subscale α .68.	-	Patient and expert interview. Expert review. Pilot test.	Factor analysis confirmed multidimensional structure. Correlated with FLIC. Divergent validity; poor correlation with Marlowe-Crowne Social Desirability Scale	All domains but social desirability sensitive to change in performance status.	Time: 8 minutes. Acceptability not known.	Outpatient.	Patients with lung cancer. Age range 36 to 80	English and other languages
McGill Quality of Life Questionnaire ^{338,424-426}	16 items plus single-item global scale. 5 domains; physical well-being; physical symptoms; psychological; existential well-being; support	Patient completion	Ten-point categorical scale	Overall Cronbach's α .83. Subscales α .65 to .87	Test-retest correlations .62 to .85 for subscales. N=100, time=2 days	Literature. Clinical experience. Interviews with patients	Correlated with the single-item QL measure and Spitzer QL Index.	Scores different on good, average and bad days.	10 to 30 minutes. Acceptability: 0.001% missing data (4 of 3271 items)	Community. Inpatient. Outpatient.	Cancer patients, all stages, including palliative care. All ages.	English and French.
McGill Quality of Life Questionnaire – Cardiff Short Form ⁴²⁷	8 items; 3 domains: physical symptoms, psychological and existential, plus global QL.	Patient completion	Ten-point categorical scale	Overall Cronbach's α .68 to .80. Subscales α .46 to .86	Test-retest correlations .51 to .86 for items. n=48, time=1 week	Clinical experience inc. use of original MQOL	Items correlated with original MQOL domains and own domains		1 to 8 minutes (mean 3). Acceptability: 98.2% patients reported 'clear' or 'very clear'	Inpatient. Outpatient.	Cancer patients under palliative care service. Age range 27 to 88	English

Table 6.6. Psychometric qualities of shortlisted HRQL instruments												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
McMaster Quality of Life Instrument ⁴²⁸	32 items; 4 domains: physical, emotional, social and spiritual.	Patient completion; carer and staff completion	Seven-point categorical scale	Cronbach's α subscales α .62 to .79	Test-retest correlations .83 to .95 for subscales.	Literature . Clinical experience. Pilot test.	Correlated with the Spitzer QL Index	Scores changed in relation to whether patients felt they had changed	3 to 30 minutes	Inpatient Outpatient Community	Patients under palliative care services . Age range 29 to 95.	English

Table 6.7 Content appraisal of short listed instruments against domains of need for SPC derived from content analysis						
	EORTC QLQ-C30	EORTC QLQ-LC13	FACT-L	McGill *	McGill Short Form *	McMaster
Pain	✓	✓	✓			✓
Breathlessness	✓	✓	✓			✓
Nausea/vomiting	✓		✓			✓
Weakness	✓					
Fatigue	✓		✓			✓
Anorexia	✓		✓			✓
Weight loss			✓			
Ascites						
Oedema						✓
Constipation	✓					✓
Diarrhoea	✓					✓
Confusion			✓			✓
Drowsiness						✓
Incontinence						
Urinary problems						
Dry/sore mouth		✓				✓
Cough		✓	✓			✓
Mobility difficulties	✓					✓
Patient anxiety/distress	✓		✓	✓		✓
Depression	✓			✓	✓	✓
Low mood	✓		✓	✓	✓	✓
Patient not coping			✓			
Thoughts of dying			✓	✓		
Sleeping problems	✓		✓			✓
Body image concerns						✓
Deteriorating condition						
Lives alone						
Financial issues/concerns	✓					✓
Relationships with others	✓		✓			✓
Carer anxiety and stress						

* Requires respondents to list three most troublesome symptoms over the last two days

EORTC QLQ-C30 and QLQ-LC13

The EORTC QLQ-C30 is perhaps the most widely used cancer HRQL measure in Europe. It was originally developed for use in clinical trials, and has been widely tested and found to be valid, reliable and responsive in a range of populations, settings and stages of cancer, including advanced disease.⁴²⁹ It is a recommended HRQL instrument within the Toolkit of Instruments to Measure End of Life Care (TIME), a large scale project aiming to assemble a battery of suitable questionnaires to measure quality of care at the end of life.⁴³⁰ It is the core questionnaire of the EORTC's modular approach to HRQL assessment, with optional disease-specific modules capturing diagnosis-related symptom issues in greater depth. The EORTC QLQ-LC13 is the lung-cancer specific instrument developed for use with the core EORTC QLQ-C30.⁴²² It covers lung-cancer related symptoms and treatment side-effects. It is extensively used in trials of lung cancer chemotherapy and radiotherapy and has strong evidence of reliability and validity at all stages of lung cancer. To measure multi-dimensional HRQL, however, it must be used in conjunction with the core questionnaire, forming a 43-item instrument.

The EORTC HRQL measurement system is based on a multidimensional quality of life construct comprising core items relevant to all cancer patients, supplemented by diagnosis and/or treatment-specific items.⁴³¹ Within this modular approach, the core construct encompasses physical function, role function, cognitive function, emotional function, social function, key symptoms including fatigue, pain and nausea and vomiting, and financial impact of the disease. Guidance for the development of EORTC modules has been published; HRQL issues are generated through literature searches, interviews with health care providers, and interviews with patients, before these issues are operationalised into questions, piloted, and tested.⁴³²

The EORTC QLQ-C30 has 30 questions, arranged either as multi-item scales, or single items. It has five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (pain, nausea and vomiting and fatigue), and a global health and quality of life scale. Additional single items cover symptoms including difficulties sleeping and shortness of breath, as well as the financial impact of the disease. The EORTC QLQ-LC13 (13 items) also uses a mixture of multi-item scales and single items to cover common lung cancer symptoms (cough, dyspnoea, haemoptysis) in more depth, together with treatment side effects. The time scale for both is how the respondent has felt during the last week.

The EORTC group have published a manual to provide guidance on the correct scoring of the EORTC QLQ-C30 and LC13 instruments.⁴³³ The QLQ-C30's five functional scales, three symptom scales, global QL scale, and six single-item symptom measures are scored from 0 to 100. Higher scale score represent a higher response level, meaning that high scores on symptom scales represent a high level of symptoms, but high scores on the functional scale indicate a high (good) level of functioning. The scoring procedure for each scale involves:

1. An estimation of the raw score (the mean of the items within each scale)
2. The linear transformation of the raw score to a range between 0 and 100 using the appropriate formula (supplied by EORTC).

The scoring system is applied in exactly the same way to the LC-13, which has one multi-item scale on dyspnoea, and single-items for other symptoms. For either instrument it is not possible to calculate a total score.

The EORTC system is widely used within cancer clinical trials. It is psychometrically robust, with a clear grounding in multidimensional concepts of HRQL, and has been subjected to a rigorous developmental process. It is also apparently comprehensive in its coverage of the concerns of lung cancer patients. However, when both instruments were compared against the items of need identified through the ethnographic study [Table 6.7, page 256], they together covered 17 of the 30 different domains of need. They were particularly strong on key symptoms, with issues such as pain and nausea and vomiting being covered in depth by scales rather than single-items. They also covered key issues of need such as relationships with others and financial concerns. However, they did not cover other identified common symptoms such as urinary problems, ascites and oedema, or important psychological considerations such as coping ability, thoughts of dying and body image concerns.

The scoring system of the EORTC may also restrict its suitability as an indicator of need for SPC. The EORTC QLQ-C30 alone generates 15 separate scores, which cannot be combined. Statistically, it may therefore be challenging to employ this instrument in a cross-sectional survey to grade levels of total need, unless the global quality of life score is used as the indicator of need.

FACT-L

FACT-L is a 44 item instrument also widely used in lung cancer research, formed of a core set of HRQL items (known as the FACT-G), with a further 9 lung-cancer specific items.⁴²³ Its domains encompass physical, social/family, emotional and functional wellbeing, as well as lung-cancer specific symptoms. It has undergone comprehensive psychometric testing, although its reliability and validity are not as robustly understood as with the EORTC

QLQ-C30. Along with the EORTC, the FACT-G/L was also recommended for use as a HRQL instrument in palliative care populations by the TIME (Toolkit of Instruments to Measure End-of-Life Care) project.⁴³⁰

The FACT measurement system of which the FACT-L is part defines HRQL as having four major dimensions – physical wellbeing, emotional wellbeing, social wellbeing and functional wellbeing. Symptoms are part of, rather than something influenced by, HRQL.⁴²³ Items for this instrument were generated through interviews with patients and health care professionals, and shortlisted by an expert panel.⁴²³

The current Version 3 of the FACT-L incorporates 44 items in six areas; physical, social, emotional and functional well-being, a respondent's relationship with their doctor, and additional lung-cancer specific concerns including shortness of breath and weight loss. As with the EORTC, the time scale for the FACT-L is the previous seven days.

The FACT-L can be used to calculate both a total score, and sub-scale scores (covering physical, emotional, social and functional wellbeing). Sub-scales are scored by adding or subtracting (depending on the wording of the question) scores for each item; the total score is a sum of each sub-scale score. Higher scores indicate a more positive quality of life. The maximum total score is 136.

When the instrument items were compared against the domains of need for SPC, 14 of the 30 identified areas were included. FACT-L items focused on similar issues to the EORTC, in the main on key symptom concerns, and psychological problems including ability to cope.

The ability to calculate a total score for FACT-L makes it more feasible than the EORTC to use as an indicator of need for SPC, but its omission of important domains including financial concerns means it is not as comprehensive.

McGill Quality of Life Questionnaire and the McGill Quality of Life Questionnaire – Cardiff Short Form

Developed to be suitable for use at all stages of cancer and other life-limiting illnesses, although originally tested in advanced cancer patients, the 17-item McGill Quality of Life Questionnaire is widely used within palliative care research.^{338,424-426} It has strong psychometric properties including responsiveness to change. A particular feature is its inclusion of a number of items to measure existential issues, seen by the authors as crucial to HRQL in patients with progressive disease. The McGill Quality of Life Questionnaire does not, however, ask about specific symptoms, instead requesting respondents to list and rate the three most troublesome symptoms for them over the last two days. In the context of the present study, this may prevent the assessment of the association of particular concerns such as pain and breathlessness with SPC use. A shortened version, the McGill Quality of Life Questionnaire – Cardiff Short Form – has also been recently devised and tested in patients receiving palliative care.⁴²⁷

The McGill Quality of Life Questionnaire covers four general domains of HRQL (physical, psychological, existential and support), and defines quality of life as subjective well-being.³³⁸ As noted above, physical symptoms are not, however, explicitly defined; instead, respondents are requested to list the three physical symptoms which have been the biggest problem over the last two days. The instrument places a particular focus on the existential aspects of HRQL, with items covering concerns about death, freedom,

isolation and meaning. It also considers both positive and negative influences on quality of life.⁴²⁵ McGill items were derived from patient interviews, a literature review, and existing HRQL instruments including the FLIC.³³⁸

The McGill questionnaire can generate a total score. Firstly, item scores are recorded where necessary to ensure that a score of 0 indicates the least desirable state, and a score of 10 the most desirable. If respondents state that they have no, or less than three symptoms, a score of 10 is assigned to each symptom item which indicates 'none'. Sub-scale scores (physical, psychological, existential and support) are calculated by determining the mean of the items contained within each sub-scale. The total score is calculated as the mean of the scores of the four subscales and the physical well-being item. Therefore, each item, sub-scale and the total score can range from 0 to 10.³³⁸

The McGill Quality of Life Questionnaire is widely used within palliative care. However, when items were compared against the listed domains of need for SPC, the long form covered only 4 of the identified areas of need, and its short form only 2. This was in large part accounted for by its lack of items on specific symptoms. Additionally, the McGill includes a number of extra items with a particular focus on how purposeful respondents feel their life is, how good they feel about themselves, and how much control they have over events. These were not identified as key domains of need for SPC.

McMaster Quality of Life Scale

Also developed to assess HRQL in palliative care patients, the 32-item McMaster Quality of Life Scale covers dimensions including physical symptoms, functional status, social functioning, emotional status, cognition,

sleep and rest, energy and vitality, general life satisfaction and meaning of life.⁴²⁸ It has good psychometric properties in patients with advanced disease; symptoms and issues were derived from monitoring patients under palliative care teams.

The developers of the McMaster Quality of Life Scale define HRQL as covering four key dimensions: physical, emotional, social and spiritual.⁴²⁸ Items for the instrument were initially generated by an expert panel of palliative care specialists and a researcher, based on a review of the literature. Symptoms of palliative care patients were also monitored and included within the instrument before psychometric testing was undertaken.

The instrument asks respondents to rate their experience over a list of areas, covering key physical symptoms (including pain, nausea and vomiting, breathlessness), activities of daily living, social interaction and issues such as meaning of life and future planning. Its time frame is the past day as the developers argue palliative care patients may change rapidly.

The instrument generates a total score. Values on the 7-point response scales are recoded so that all items are rated in the same direction, with 1 being the most negative response and 7 the most positive response. An overall score can then be calculated by simple addition; scores for two subscales (physical and non-physical) can also be calculated. Adjustment was made by the instrument authors for missing items by dividing the total scores by the number of items rated, and then multiplying by 32, the maximum number of possible responses.⁴²⁸

Content appraisal of the instrument against the identified major domains of need for SPC found that the McMaster scale had the most extensive

coverage, including 20 of the 30 need dimensions. This extensive coverage, together with the ability to calculate a total score, suggest this instrument may be well suited to use as an indicator of need.

Choice of HRQL instrument as an indicator of SPC need

Of the six shortlisted instruments reviewed above, inevitably none cover all the potential domains of need for SPC identified through my ethnographic study. Five domains of need are excluded from all instruments (ascites, incontinence, urinary problems, deteriorating condition, and living alone). Whilst the first three symptoms are not major indicators of need, the concept of a deteriorating condition is a powerful determinant of continuing SPC input. Living alone is also, in the presence of uncontrolled symptoms, a potential trigger of specialist care. However, it is possible that information on these latter two may be gathered from patient report and medical records. This is discussed further in the following chapter.

Two instruments, the EORTC QLQ-C30/LC13 and the McMaster Quality of Life Instrument, cover the identified domains of need in most detail. However, the most comprehensive coverage is within the McMaster Quality of Life Instrument. Further, in comparison to the multiple scale scores derived from the EORTC QLQ-C30, the McMaster provides a total score which could more readily be used to reflect need for SPC. It is not as extensively tested or used as the EORTC, though its authors claim it reaches acceptable levels of reliability, validity, and acceptability. Thus, of the two, I decided to use the McMaster QLI as an indicator of need for SPC within the cross-sectional survey of lung cancer patients. However, its performance would require thorough testing through a piloting process to ensure it was a suitable instrument for use within this setting and population.

Assessing carer anxiety and distress

I add a final note here on the role of carer anxiety and distress in determining need for SPC. Whilst carers' issues were rarely central to discussions about referrals to SPC, they were a common and noticeable presence as the needs of patients were being considered. A carer who was not coping led to concerns about the unmet needs of patients. The role of carers was formally recognised in the referral scoring system used within RS1 to prioritise inpatient referrals, which included a score for carer emotional and psychological stress. A high carer score (the maximum of three) could ensure that a particular referral was prioritised for inpatient care over other patients. Thus, carer psychological needs form one, important, aspect of a patients' overall need for SPC, and this was recognised within the framework of SPC need derived from my observations.

The role of carer stress in determining need for SPC meant that I aimed, within the cross-sectional survey, to recruit carers as well as patients. I planned to use carer data in an exploratory analysis considering the association between carer stress and SPC use. Inevitably, carer stress is not assessed within HRQL instruments aimed at patients. A suitable instrument to measure carer stress was therefore required. A comprehensive systematic review of self-report caregiver instruments used in cancer had already been recently undertaken.⁴³⁴ This identified 28 instruments in three categories: caregiver burden (17 instruments), caregiver needs (8 instruments) and caregiver quality of life (3 instruments). Following the appraisal of instruments for their psychometric properties and likely ease of administration, the authors made a number of recommendations for the most appropriate instruments to use in each category. In the area of caregiver quality of life, Weitzner's Caregiver Quality of Life Index – Cancer

(CQOLC) was recommended as being rigorously developed and extensively tested.^{435;436}

The CQOLC is a 35 item instrument using a 5-point Likert scale. Items cover a multi-dimensional concept of quality of life, including emotional and psychological distress, activities of daily living, relationship with the patient, social support, and financial concerns. It has been demonstrated to have adequate validity, test-retest reliability and internal consistency.^{435;436}

However, its development remains confined to the US hospice care system, and it has thus not been validated for use within a UK setting. Further, its ten-minute completion time may be excessive when the particular domain of need I wished to assess was caregiver stress, rather than a multi-dimensional concept of quality of life.

In the light of these concerns, I therefore considered alternative instruments. Following discussion with experts and practitioners in the field, I decided that the General Health Questionnaire 12 item version (GHQ-12) was suitable to take forward into the piloting process. The GHQ was developed as a screening instrument to detect general psychological distress, and is used worldwide in both healthy and ill populations.⁴³⁷ The shortest version, the GHQ-12, has been found to be as robust as longer versions.⁴³⁸ It was designed to be self-administered, and comprises twelve questions covering the respondent's experience of anxiety and depression, general level of happiness, and sleep disturbance. Its specific focus on psychological distress and its short completion time recommended it as the most suitable instrument within the exploratory study on carer stress and SPC use.

6.5 Conclusions

In this review and critical appraisal of HRQL instruments developed for use in lung cancer and palliative care populations, I considered the psychometric properties, conceptual relevance, and applicability of a range of instruments in searching for a valid and reliable indicator of need for SPC. Many instruments were poorly psychometrically tested, and were thus excluded from further consideration. Of those which met minimum standards of reliability and validity, few were suitable for use in cancer patients at all stages of disease, and covered a truly multidimensional concept of HRQL.

However, through this review and appraisal I did locate more than one instrument which is both well matched to the identified criteria of need for SPC, and has undergone sufficient psychometric testing. I chose the McMaster QLI to take forward to the pilot study of SPC use. In spite of the existence of a number of instruments designed to assess the needs, burden and quality of life of carers of cancer patients, concerns with their validity and suitability led me to choose the GHQ-12 as an approach to assessing carer stress.

In the next chapter, I describe the cross-sectional survey methods used to determine use of SPC in relation to age, after controlling for need. I explain the study setting, design and piloting of the study instruments. I then outline the conduct of the study, including determination of the sample size, recruitment, and data preparation and analysis. Finally, I present my findings on the equity of use of SPC within the study setting, and relate these to previous research on variations in use of SPC.

Chapter 7

Equity of use of specialist palliative care: cross-sectional survey

All animals are equal but some animals are more equal than others.

George Orwell. *Animal Farm*.⁴³⁹

The NHS Cancer Plan states that 'all patients should have access to the specialist palliative care advice and services that they need.'¹³ The NSF for Older People highlighted concerns that older people may have more limited access to SPC services in comparison to younger patients.⁷ This point was reiterated in later reports from the House of Commons Health Committee on Palliative Care, and WHO Europe.^{18;440} A systematic review of referral to and use of SPC services in relation to age, conducted as background to this study, found that there was evidence of inequalities for older patients.¹⁵ All of the studies included in the review reported a statistically significant lower use of SPC among older cancer patients (predominantly aged 75 and above) at a univariable level (crude odds ratios ranged from 0.33 (0.15 to 0.72) to 0.82 (0.80 to 0.82)).^{102;119-121;123-126;128-131;133;134}

However, these studies did not comprehensively investigate and control for patients' clinical and psycho-social needs for care. Therefore, we cannot draw reliable conclusions about the extent to which use of SPC is equitable (reflects the need for care) for older patients.²² Furthermore, studies have rarely considered the needs of carers as well as patients in determining use, in spite of the stated aim of SPC to improve quality of life for patients and their families.²⁷

Prospective research on the use of SPC by cancer patients is challenging, due to the terminal nature of illness, fear of burdening participants, loss of data due to participants' incapacity or death, and ethical considerations on research within such a vulnerable population.⁴⁴¹ Rather than the non-investigation of this area, these complications necessitate the design of high quality research with careful data collection and analysis.²²¹ In particular, researchers need to pay special attention to the handling of missing data, which is frequently missing not at random due to the deterioration of study participants: the choice of imputation method and its effect must be reported in full.⁴⁴² The strongest observational study design, a prospective cohort study, enables data to be gathered on the whole patient pathway from diagnosis to death. This may be particularly important in examinations of use of SPC as (a) access may depend on treatment decisions made on diagnosis, and the subsequent care pathways patients follow, and (b) SPC may only be used in the terminal phases (even the last few days) of a patient's illness.

To achieve the most reliable and complete understanding of equity of use of SPC, I initially planned a prospective cohort study. I aimed to recruit and follow up older and younger groups of cancer patients, and their carers, to determine use of and need for SPC services over the course of their treatment and care. However, a series of meetings with cancer nursing professionals, and the observation of the conduct of two cancer outpatient clinics, raised a number of questions about the viability of conducting a cohort study [Table 7.1].

Table 7.1 Issues in the conduct of a prospective cohort study	
Design issue	Concern arising
Optimal time to recruit patients	Patients referred to SPC before definitive diagnosis would be excluded as already have outcome of interest at baseline. Sampling bias may arise if younger patients more likely to be referred at this stage
Frequency of follow-up	Patients may be too ill or have died before first follow-up. A check on status would therefore be necessary with GP or lung nurse before each contact
Conduct of follow-up	Maintaining recruitment and follow-up within the necessary sample size may be difficult with only one researcher. Calculations show at peak data collection likely to be insufficient time to recruit and conduct follow-ups
Measuring need	Would have to use carer report on need during last stage of patient's life, compared to patient report at earlier stages. Concerns include (a) ethical issues in discussing post-bereavement interviews at recruitment to study early in disease course, and (b) difficulties in reconciling carer versus patient reported need

In the light of these challenges, I explored the alternative of a cross-sectional study. Cross-sectional studies determine a participant's exposure and outcome of interest simultaneously, usually at one point in time.⁴⁴³ They are frequently less resource-intensive than cohort studies. A cross-sectional study would involve the recruitment of older and younger groups of cancer patients to determine their current need for and use of SPC services at the time of participation.

A major limitation of cross-sectional designs is the difficulty in establishing a causal relationship between the exposure and outcome of interest, as both are measured at the same point in time.⁴⁴⁴ Difficulties in interpretation may arise as it is not possible to know the direction of the association; is the exposure responsible for the outcome, or is the outcome responsible for the exposure? However, for the topic under consideration, the primary exposure of interest is a personal characteristic (age). Difficulties in understanding the direction of any association do not therefore arise, as use of SPC cannot influence age. What cannot be assessed is whether there are delays in referral

to or use of SPC in relation to age. However, within the available resources, a cross-sectional study became the chosen approach.

In this chapter, I report in detail the design of my study to assess equity of use of SPC in relation to age. I outline the process of setting up the study, selecting outcome and explanatory variables, piloting instruments and approaches and calculating the required sample size. Full details of the data collection procedure and the data analysis undertaken are given. Next, I outline the major results from the survey, covering the characteristics of the sample, the proportion using SPC services, and the factors associated with the receipt of such care. Finally, I consider the strengths and weaknesses of the study, the results in comparison with existing literature, and offer a final summary and interpretation of the findings.

7.1 Aim and objectives

The aim of this phase of work was to investigate equity of use of SPC services in relation to age.

I decided to conduct my research amongst lung cancer patients. This was for three simple reasons: lung cancer has a high incidence, a short prognosis, and a frequently heavy symptom burden. Ready access to a relatively large population of newly diagnosed patients (lung cancer diagnoses represent around 13% of all cancer diagnoses ²⁵⁴) enables a swifter achievement of the desired sample size. A short prognosis (around 25% of patients diagnosed with lung cancer are alive one year later ²⁵⁴) increases the likelihood that referrals to SPC will be made earlier in the disease course. Finally, the difficulties of managing lung cancer symptoms, which are often complicated by the presence of comorbidities such as COPD, suggest an important role for SPC in a large proportion of cases. ²⁵⁰

The objective of this research was thus to conduct a cross-sectional survey to measure the use of SPC services by younger (< 75) versus older (\geq 75) lung cancer patients, after controlling for need.

This aim is confined to horizontal equity (equal use for equal need) rather than vertical equity (unequal use for unequal need). Investigation of aspects of vertical equity – for example, the association of use of SPC with age after controlling for need at each level of severity of lung cancer – requires multivariable analyses with effect modification. Subsequently, a much larger sample size is required. Whilst comprehensive studies into equity should consider both dimensions,⁷⁰ due to time and resource limitations within the current research it was not feasible to include a vertical component.

Further, I did not set out to investigate the relationship between age and need for SPC. One possible explanation for a lower use of SPC by older patients is that their need for SPC is also lower. Little research has been conducted in this area, and the specific relation of a measure of need to use of SPC would thus be useful. However, this would of necessity be secondary to the principal aim of this study, and be undertaken on an exploratory basis. The sufficiency of the proposed sample size to achieve this was questionable, and thus I decided to exclude this from the analysis.

7.2 Study design

Investigation and choice of setting

As discussed in Chapter 4, the diagnosis and treatment of lung cancer can take a number of paths. To conduct a comprehensive study of variations in use of SPC by lung cancer patients, ideally recruitment would cover all potential settings, including primary care, A&E, inpatient hospital, and

outpatient hospital [Figure 7.1]. This would ensure that, however patients were diagnosed and whatever subsequent treatment they received, they were included in the assessment of equity of use.

However, to conduct a viable study of the use of SPC within the resources available, it was not possible to recruit lung cancer patients from multiple settings. NICE guidance on the diagnosis and treatment of lung cancer states that patients with suspected lung cancer should be referred to a member of the lung cancer multi-disciplinary team, usually a chest physician, for further investigation and diagnosis.²³⁷ Unless the patient is already a hospital inpatient when the suspected diagnosis is raised, these referrals are routinely seen within the outpatient setting. To reflect NICE recommendations, I therefore chose to include only those patients attending outpatient lung cancer clinics. These clinics include both chest and oncology clinics, depending on whether patients are being diagnosed, treated or followed-up. I therefore excluded from this study all patients who did not attend lung cancer outpatient clinics. The limitations arising from this choice of study setting are considered further in the discussion at the end of this chapter.

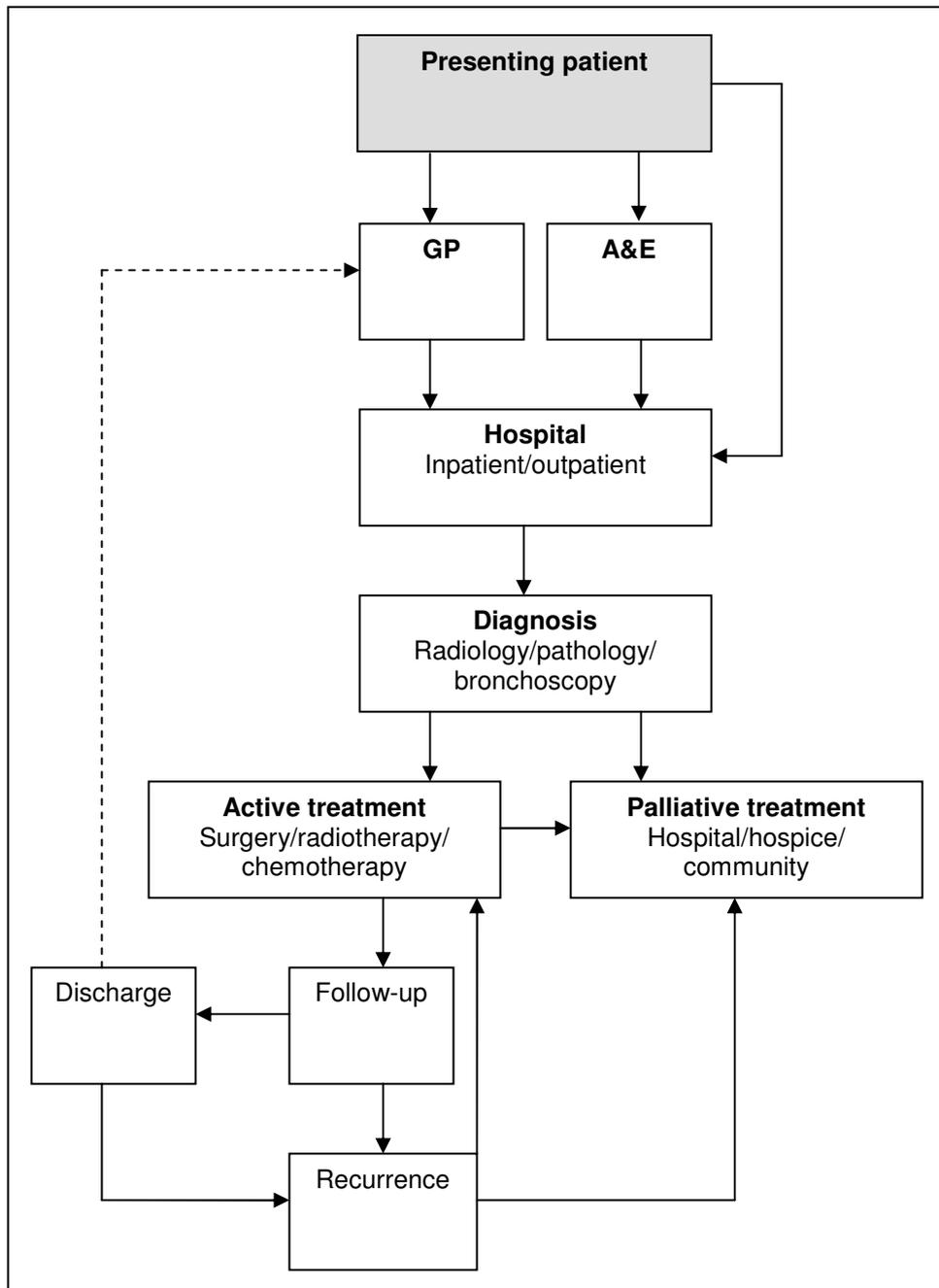


Figure 7.1 Lung cancer diagnosis and treatment pathway

Participating clinics

I chose lung cancer outpatient clinics from within the cancer network in consultation with the participating cancer research network. As a Medical Research Council (MRC) funded project, the study was automatically included within the cancer research network's official portfolio of research.

Studies within this portfolio are coordinated to avoid patients being over-researched. Whilst there were no other epidemiological or health services research studies recruiting lung cancer patients at the same time as this study, there were a number of long-standing clinical trials recruiting from the two clinics which had a research nurse (the cancer centre and one of the cancer units). It was therefore agreed with the cancer research network that, whilst I could recruit from these clinics, I would not approach patients already participating in a clinical trial.

There are six NHS Trusts providing lung cancer outpatient services within the network, organised as four cancer units and one cancer centre. Figure 7.2 shows the lung cancer outpatient clinics chosen to participate in the study. The cancer centre spans two NHS Trusts, one of which has two hospitals. Within the cancer centre, dedicated lung cancer clinics take place at two of the three hospitals. I chose to recruit only from one of these hospitals, selecting the hospital which ran the major lung cancer clinic for the centre. Three of the four cancer units within the area were then selected to participate in the study, chosen to reflect different geographical locations within the network.

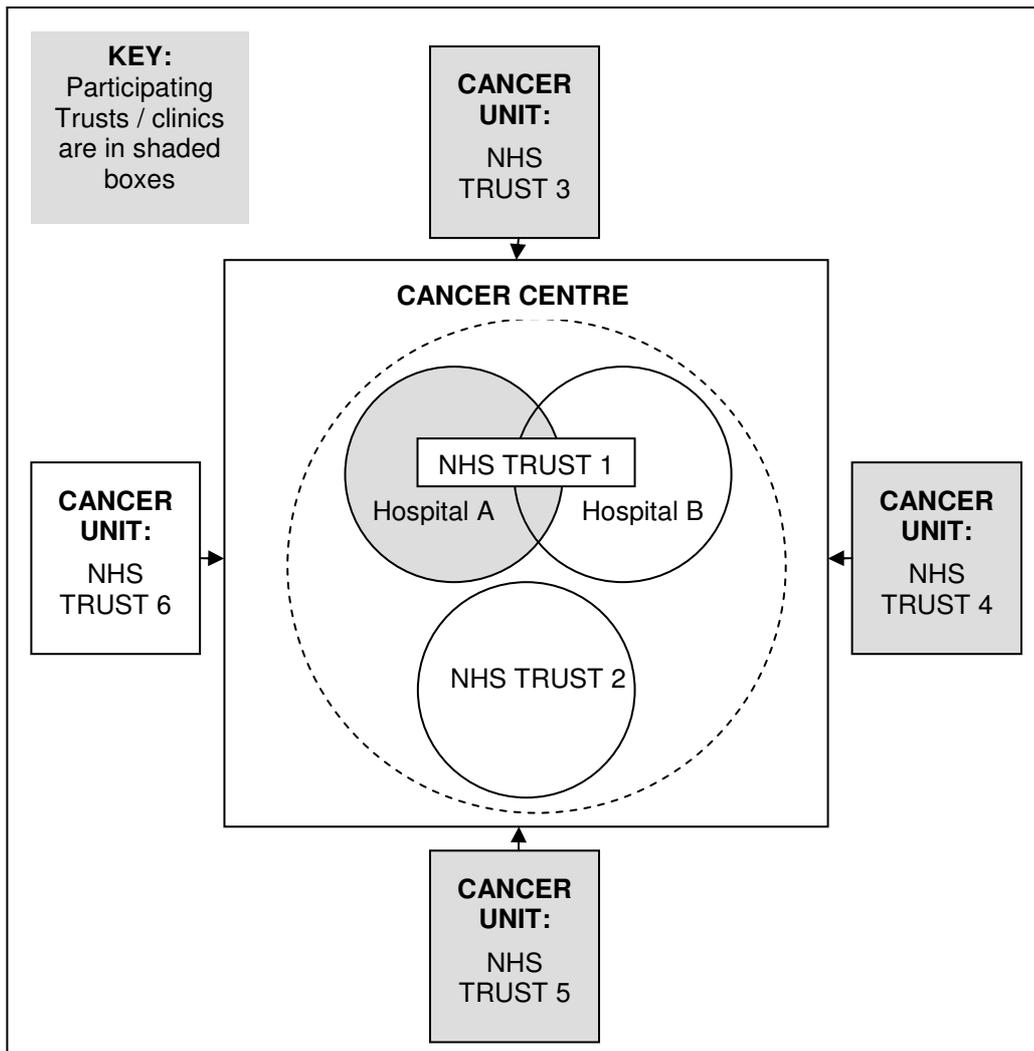


Figure 7.2 Participating lung cancer clinics within the cancer network

Each of the four participating sites varied in their lung cancer clinic organisation and the medical specialties available to treat patients. These are summarised in Tables 7.2 and 7.3.

Table 7.2 Summary of lung cancer clinics at participating sites				
Site	Type	Chest clinic	Medical oncology clinic	Clinical oncology clinic
1	Cancer unit	✓ weekly	✗	✓ weekly
2	Cancer unit	✓ weekly	✗	✗ referred to site 3
3	Cancer centre	✓ weekly	✓ twice weekly	✓ weekly
4	Cancer unit	✓ weekly	✗	✓ twice weekly

Table 7.3 Details of lung cancer clinics at participating sites				
	Site 1	Site 2	Site 3	Site 4
Type of clinic	Cancer unit	Cancer unit	Cancer centre	Cancer unit
Services offered	Respiratory medicine & clinical oncology	Respiratory medicine	Respiratory medicine, clinical oncology, medical oncology	Respiratory medicine & clinical oncology
Times of clinics	One day a week (morning lung clinical oncology list; afternoon clinical oncology and respiratory medicine)	One day a week	Three days a week. Main clinic runs all day: respiratory medicine, clinical & medical oncology. Second weekly oncology clinic. Third weekly oncology clinic for site 2 referrals.	Two clinics a week. Small clinical oncology list one afternoon; main respiratory medicine & clinical oncology clinic another day.
Patients seen	Suspected & diagnosed lung cancer patients. Other cancer site & respiratory patients seen occasionally.	Mixed: suspected & diagnosed lung cancer patients and other respiratory patients.	Mixed: suspected & diagnosed lung cancer patients and other respiratory patients. Thymoma & mesothelioma cases, although separate mesothelioma clinic also run.	Mixed: suspected & diagnosed lung cancer patients and other respiratory patients. Clinical oncology not exclusively lung cancer; colorectal & some other cancer sites.
Treatment offered	Chemotherapy on site. Radiotherapy referrals to cancer centre.	Chemotherapy only for SCLC patients. NSCLC chemotherapy & all radiotherapy referrals to cancer centre.	Offers most possible chemotherapy & radiotherapy regimes.	Chemotherapy primarily for SCLC patients. Most NSCLC chemotherapy & all radiotherapy referrals to cancer centre.
Lung MDM	Lunchtime on clinic day.	Morning prior to clinic.	Morning prior to main weekly clinic.	Morning prior to main weekly clinic.

Due to clashes in the timing of clinics, I was not able to recruit from every clinic run at the research sites. In particular, sites 2 and 4 run their clinics on the same day. I therefore recruited from these in two phases, concentrating on recruiting from site 2 for three months before switching to recruit from site 4. Table 7.4 summarises the weekly timetable of clinics attended.

Table 7.4 Timetable of attended lung cancer outpatient clinics					
	Monday	Tuesday	Wednesday	Thursday	Friday
AM	Site 2 / Site 4	-	Site 1	-	Site 3
PM	Site 2 / Site 4	Site 3	Site 1	-	Site 3

Participants

Patients were eligible for inclusion in the study if they had a histologically or clinically confirmed diagnosis of primary lung cancer (NSCLC or SCLC) and the ability to fully understand consent procedures and complete study instruments in English.

I developed ineligibility criteria in consultation with clinic staff, to avoid distressing patients at particularly sensitive times. There were two categories of ineligibility; (i) patients ineligible at that point in time, who may become eligible in the future, and (ii) patients who were and would remain ineligible. The former category included patients receiving diagnoses or news on disease progression, or who required immediate medical attention. I did not feel it was suitable to approach these individuals at that point in time. However, on attendance at future clinics they were eligible to be approached. The latter category, those who were permanently ineligible, included patients attending participating clinics who were unable to communicate in English, who were participating in a clinical trial, or who did not have a diagnosis of primary lung cancer. Full details of the ineligibility criteria are in Table 7.5.

Table 7.5 Ineligibility criteria	
Patients not approached but who may become eligible at a later clinic	
Category	Explanation
Under investigation for lung cancer	If diagnosed, will become eligible at future clinic visits.
New diagnosis of lung cancer	It was not possible or appropriate to approach patients on the day of diagnosis. Additionally, it was not felt to be ethical to approach patients who were still unsure about their future course of treatment and likely prognosis. A small proportion of these patients will go on to have surgical intervention for their lung cancer and thus remain ineligible for the study.
Lung cancer diagnosis but receiving test results on disease progression	Those attending clinic for the results of tests as to whether their disease had progressed (e.g. the discovery of metastases or new metastases, or relapse following treatment) may be particularly anxious and distressed. It was not felt to be appropriate to approach them at this time.
Lung cancer diagnosis but too ill or distressed	This category included both physical and mental health issues which rendered patients unsuitable to approach for participation in the study. Patients in this category were usually identified by clinic staff, and included those with psychiatric issues. A small proportion of patients attend outpatient clinics requiring urgent medical attention and inpatient admission. In all cases, it was not appropriate to approach such patients about this study.
Ineligible patients at time of screening for study: will remain ineligible	
Category	Explanation
Non English speaker	It was not possible within the resources of the study to provide interpreters for those patients who were unable to communicate in English.
Complete surgical resection of histologically confirmed lung cancer, with or without adjuvant therapy.	Patients who had undergone surgery with the aim of cure. Patients who had previously undergone surgery but had relapsed were eligible for the study.
Not aware of [usually clinical] diagnosis of lung cancer	If patients were unaware of their diagnosis, it was not possible to approach them about the study.
Participating in a clinical trial	Such patients do not receive standard care, as they are treated according to a strict protocol and are in regular contact with a dedicated research nurse. Therefore, their inclusion in an observational study would not be appropriate.
Not lung cancer patients	Patients with mesothelioma, with other primary cancers (including those with cancers which had metastasised to the lung), and with other respiratory illnesses also attended these clinics, and were excluded.

The ethnographic work I conducted in phase one identified that informal carer's needs may be taken into account when defining patient's need for SPC. In particular, carer stress was included in documentary assessments of need for SPC. Therefore, I also approached informal carers (including spouses, partners, other family members or friends) who attended clinics with eligible patients to ask if they would participate in the study.

Identification of eligible participants

I identified potential participants prior to the start of each clinic from the clinic appointment list, and by additional screening of clinic notes [Figure 7.3]. I marked eligible patients on the clinic clerk's lists to alert them that I wished to approach these patients about the study. This helped in the identification of eligible patients as they arrived in the clinic.

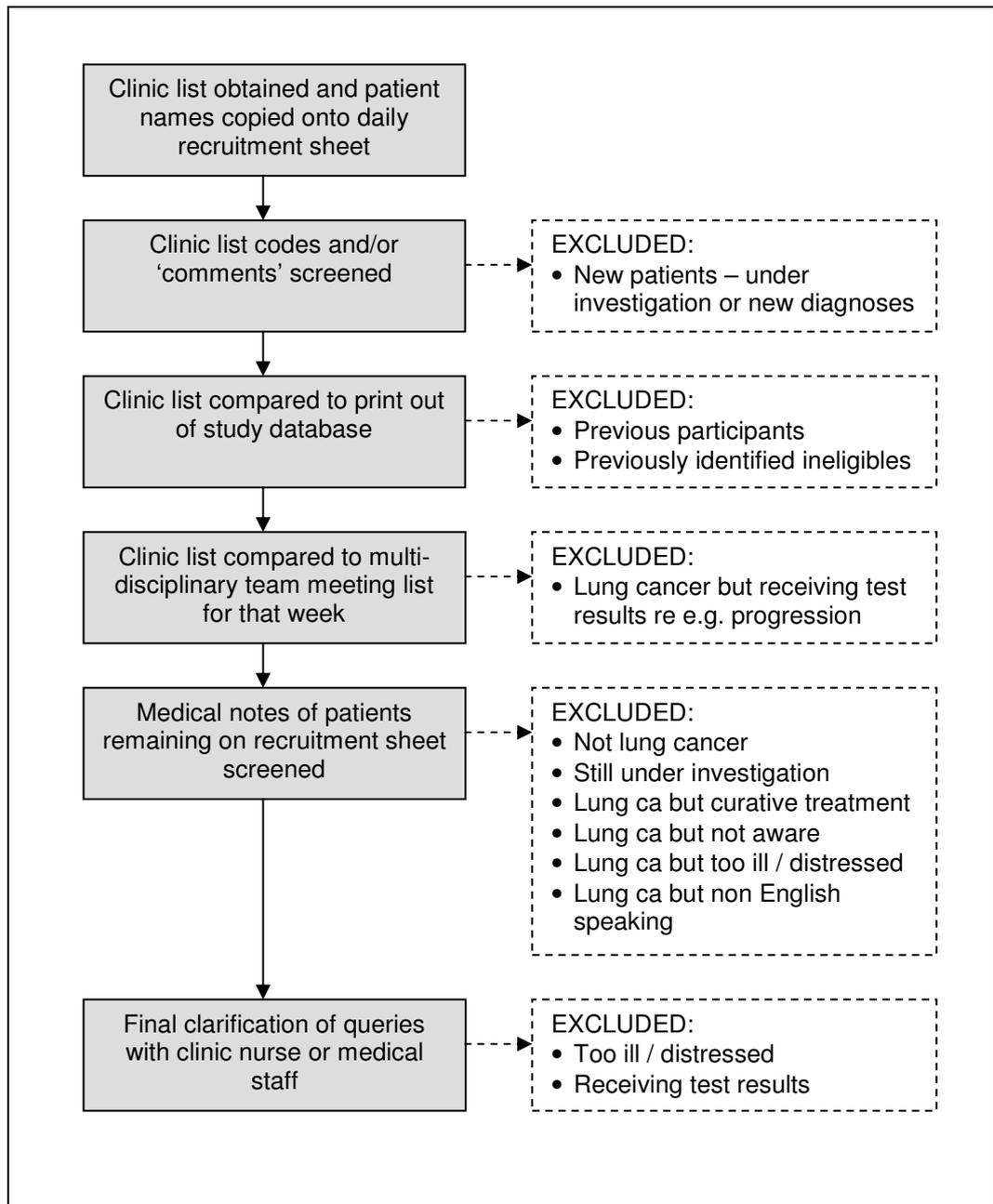


Figure 7.3 Determining eligible patients in each clinic

Recruitment procedures

I used identical recruitment procedures in all four clinics. On their arrival in the clinic waiting area I identified all eligible patients and their carers (sometimes with the help of clinic staff), and approached them to introduce myself and the study. I explained the aim and nature of the study verbally and answered any questions. Patients and carers who expressed an interest

in participating then received individual study information packs containing an information sheet, consent form and the relevant questionnaire. I asked patients and carers to read through the information about the study and complete the consent form and study measures whilst in the clinic, usually prior to seeing the doctor. Those who expressed an interest in participating, but wished to complete the instruments following the clinic, were provided with a freepost envelope to enable them to return questionnaires once completed. As far as possible, however, I obtained written consent from such participants whilst in the clinic, to enable me to extract data from their notes.

I asked participants to complete the study measures themselves where possible. However, I offered patients or carers who had difficulties reading or writing due to visual impairment or disability the option of being read the questions and writing down their answers. This could be with a family member or friend who was attending clinic with them, or with me.

Following completion of the study instruments by the patient, and the receipt of a completed consent form, I extracted further data from the patient's medical notes using a form I developed and piloted for this purpose (Appendix V, page 460). Data extraction usually took place at the end of a clinic, after the patient had seen the doctor. This allowed for any decision to refer to SPC on that occasion to be noted, as the doctors wrote up all clinic encounters by hand in the patient's notes.

Consent

I asked patients and carers to read through the information about the study and complete the study measures whilst in the clinic, if possible. Their consent to participate was recorded through their completion of a written consent form (see appendix V, page 435), including a section in which

patients agreed to me obtaining additional demographic, diagnosis and treatment information from their medical records. This was a non-intervention study involving the collection of basic demographic, health status and health service use data at one point in time only. Consent during attendance at the clinic followed the procedure of previous similar studies.¹⁰⁶ I was present throughout every clinic and therefore available to answer any questions patients may have had.

Ethical considerations and concerns

There is ongoing debate about the ethical questions posed by research involving patients with palliative care needs, and their carers. Expressed concerns centre around the physical and emotional health of patients and their capacity to give informed consent; placing demands on their time at the end of their life; the probability of patients feeling 'coerced' to participate; and the likelihood for participants to directly benefit (or not) from the research.⁴⁴⁵ However, the concern that research places an unacceptable burden on patients with palliative care needs is challenged by evidence that such patients and their carers welcome the opportunity to take part and use their experiences to potentially benefit others.^{446,447} Additionally, it has been argued that patients nearing the end of life have the same rights to choose to participate in research as all other patients.⁴⁴⁸ The skills of the researcher are frequently identified as crucial in ensuring palliative care research is conducted in an appropriate, sensitive and rigorous fashion.⁴⁴⁹

I endeavoured to involve health care professionals and patients in the design of the survey to ensure all ethical issues were highlighted and addressed. Lung cancer CNSs provided advice and support from an early stage. I also obtained advice from the User Involvement Partnership Facilitator in the cancer network as to how best to gain the advice of patients and carers,

particularly on the planned recruitment procedures and the content of the study materials. Following her recommendations, I distributed information about the study to the local user involvement partnership groups, and more widely to users through the Cancer Voices Opportunities for Involvement Scheme. Despite these efforts, no patient or carer came forward locally to become involved. This perhaps reflects the particular challenges in involving patients with advanced cancer in research.⁴⁵⁰ However, four patients recruited via Cancer Voices were able to offer advice on the proposed design and conduct of the survey.

As I had not been able to consult with patients and carers as extensively as hoped in the initial design stages of the project, a pilot phase of the survey was used in part to test and amend the study information and instruments in consultation with patients and carers in the participating lung cancer clinics. The pilot testing was, as a result, more extensive than originally envisaged, and considered not only the study instruments but also the research processes put in place. The pilot, with 18 patients and 16 carers, found no major concerns from participants in the procedures used to explain the study and gain informed consent. It did, however, give rise to concerns about the HRQL instrument initially chosen as an indicator of need for SPC, the McMaster Quality of Life instrument; this is discussed further in section 7.3, below. Full details of the pilot methods and results are in appendix IV, page 423.

The information sheet used throughout the study covered the following:

- the purpose of the study
- the study methods, and what their participation would involve

- that participation was purely voluntary and that they were free to withdraw from the study at any time and without giving any reason
- that any decision they make about participation would not affect their future health care or work in any way
- that their data would be kept strictly confidential in accordance with the Data Protection Act 1998, and would never be used in a way which would identify them personally
- that the research had been given a favourable opinion by the appropriate Research Ethics Committee and that all research carried out within the study would conform to strict ethical guidelines

Additionally, all participants had the opportunity to discuss any concerns prior to giving written consent. My presence in the clinic, enabling participants to answer questions and clarify issues arising, was a particular strength of the recruitment process.

I sought and received ethical approval for this phase of work from St Thomas' Hospital NHS Research Ethics Committee. I gained research governance approval separately from each of the four participating Trusts. As a result of this process, I received an honorary contract with each Trust to enable me to attend clinics to carry out the research.

Recruitment period

Recruitment to the study took place over two time periods. The first phase of recruitment took place over three months from 19 June to 13 September 2006. At this point, due to the personal reasons outlined in the Preface, I temporarily halted data collection. This interruption did, however, also have the benefit of enabling a new cohort of patients to come through; by September 2006 the majority of eligible patients attending clinics had

participated in the study and recruitment numbers had therefore dropped. The second three month period of recruitment took place from 30 January to 27 April 2007, at which point I ceased recruiting as I had achieved the desired sample size of 250.

7.3 Study instruments and variables

Participating patients and carers completed a semi-structured questionnaire compiled for the purposes of this study (see Appendix V, page 439 for the text of the patient questionnaire, and page 453 for the carer questionnaire). The patient questionnaire included 25 items covering their stated diagnosis and other illnesses, their use of health care services for lung cancer, and personal details (based on items developed for the National Survey of NHS Patients by the Picker Institute Europe and others).⁴⁵¹ In addition, the patient questionnaire included a validated HRQL instrument, the EORTC QLQ-C30, and its lung cancer module the LC-13.^{431;452}

This was not the initial choice of HRQL instrument to use as an indicator of need for SPC following my systematic review and content appraisal described in Chapter 6. In the pilot study, I used the McMaster Quality of Life instrument, as this had the most comprehensive coverage of domains of need for SPC and enabled the calculation of a total score to use as an indicator of need for care.⁴²⁸ However, the piloting process [described in full in Appendix IV, page 423] found this to be unsuitable for use in the main cross-sectional survey for four reasons:

1. There was a high proportion of missing data, with only 8/18 (44%) of respondents completing all items on the scale.
2. Patients had difficulty in understanding the 1 to 7 scoring system, often asking for assistance.

3. Items on being bedridden and on employment were seen as unsuitable by a number of pilot participants.
4. There was a tendency for respondents to use either anchor (1 or 7) as their response, leading to skewed distributions.

For these reasons, I switched to using the EORTC-QLQ C30 with the LC13 module in the main study. As outlined in Chapter 6, these instruments also had good coverage of domains of need for SPC. Whilst they do not enable the calculation of a total score, the developers of the QLQ-C30 recommend the use of the global quality of life scale score as a suitable indicator of overall quality of life. This is comprised of two items; a rating of overall health and of overall quality of life. This was used as an indicator of need for SPC, as described in full later in this Chapter. The time taken to complete the patient questionnaire ranged from ten to 30 minutes.

The carer questionnaire comprised 13 items covering their relationship with the patient; help they gave to the attending patient; and their personal details. It also included the General Health Questionnaire 12 item version (GHQ-12) as an indicator of general psychological distress. The carer questionnaire took an average of five minutes to complete.

Choice of outcome and explanatory variables

Prior to the commencement of the study I chose and defined the outcome and key explanatory variables to investigate, based on previous research in the area and the results of the ethnographic study. These were derived from patient and carer questionnaires and medical records. These are outlined in Table 7.6, and explored in more detail below.

Table 7.6 Explanatory variables			
Variable	Defined as	Categories	Source of data
Need for SPC	EORTC-QLQ C30 global quality of life score	Continuous score	Patient questionnaire
Age	Time between date of birth and date of study participation	Over / under 75	Medical records
Gender	-	Male / female	Patient questionnaire
Ethnicity	Census categories	White / non-white	Patient questionnaire
Living alone	-	Alone / living with others	Patient questionnaire
Socioeconomic characteristics	Index of Multiple Deprivation rank based on postcode of residence	Tertiles	Patient questionnaire
Extent of disease	Number and site of metastases	None / 1 or more	Medical records
Treatment received	Current line of treatment	1 st / 2 nd or 3 rd	Medical records
Known comorbidities	Recorded as having one or more from seven groups of relevant comorbidities	0, 1 or ≥ 2	Medical records
Treating clinic	Current location of care	Clinic 1-4	Medical records
Diagnosing clinic	Initial location of care	Clinic 1-7	Medical records
Carer stress	GHQ-12	Continuous and binary	Carer questionnaire

Outcome: use of specialist palliative care

The outcome of interest was use of SPC. I did not attempt to measure access to SPC, even though (as highlighted in Chapter 2) it is the facilitation of the equal opportunity to use health care, rather than just the equal use of health care, which is the ultimate goal of the NHS's commitment to equality.⁴⁵³

However, a true assessment of access requires an investigation both of utilisation rates, and of factors which may affect these utilisation rates. For example, the offer of SPC to a patient who subsequently declines this service should be included within a measure of access to SPC, but obtaining data such as these would be challenging.

I defined use as being on the caseload of a community SPC team, attending a hospice day care unit, or receiving SPC on an outpatient basis. Patients

classified as using SPC were therefore currently receiving advice and support from clinical nurse specialists, clinicians and other members of the multidisciplinary SPC team, whether by telephone, at home or in the outpatient setting. Patients who had been discharged from SPC by the time of study participation were not classified as current users.

Primary explanatory variable: Age of patient

My primary explanatory variable was patient age, dichotomised as 'younger' and 'older'. 'Old age' is frequently defined as being 65 years of age or older, as in the National Service Framework for Older People.⁷ However, I chose 75 as the threshold for older age, for two reasons. Firstly, previous research on the influence of age on lung cancer treatment has identified patients aged 75 and above as the group least likely to receive active treatment, as well as those least likely to received SPC.^{15;454} Secondly, lung cancer is frequently diagnosed at an older age, commonly between 70 and 74.

Quality of life / need for specialist palliative care

To measure need for SPC, I used two, linked patient-completed HRQL instruments, the EORTC QLQ-C30 and the LC13. Specifically, need for SPC was operationalised as global quality of life score derived from the QLQ-C30. This is a continuous rather than a dichotomous measure, reflecting my ethnographic findings which suggested the strict categorisation of patients into 'need' and 'no need' for SPC may be problematic. Drawing on my ethnographic findings, I also chose particular dimensions of HRQL (physical, emotional and social functioning, fatigue, pain, nausea and vomiting, appetite loss and dyspnoea) as indicators of specific dimensions of need for SPC to examine in an exploratory analysis of the association of these with SPC use.

Extent of disease

Extent and severity of disease may influence referral to SPC, as patients with advanced cancer may have the highest need for symptom control.¹⁹ As NSCLC and SCLC are staged differently, I categorised extent of disease simply as the presence or absence of metastases at the time of participation in the study.

Comorbidity

Comorbidity is an important determinant of treatment outcome and survival in lung cancer, and older lung cancer patients are significantly more likely to have multiple comorbidities.⁴⁵⁵ I classified comorbidity based on categories used by Janssen-Heijen et al, in turn adapted from Charlson et al^{243;456} [Table 7.7]. This classification system identifies seven comorbidities or groups of comorbidities which may impact on treatment decisions and prognosis in lung cancer patients. It provides a standardised, clinically-driven approach to measuring comorbidity. I used this to calculate the number of clinically relevant comorbidities for each participant (grouped as none, one, and two or more).

The clinically relevant comorbidities indexed using the Charlson approach include dementia, one aspect of which is cognitive impairment. Recognising that the prevalence of cognitive impairment increases with age, and that it has been associated with poorer survival rates in cancer patients, I considered screening separately for cognitive impairment.^{457;458} However, the most commonly used screening measure for cognitive impairment, the Mini Mental State Examination, is observer-rated and can take ten minutes to complete.⁴⁵⁹ With consideration of respondent burden and the increase in sample size required to include additional covariates in the analysis, I decided against introducing a separate measure of this.

Table 7.7 Classification of comorbidity	
1.	COPD
2.	Cardiovascular diseases: Myocardial infarction, cardiac decompensation, angina pectoris, intermittent claudication, abdominal aneurysm
3.	Cerebrovascular diseases: Cerebrovascular accident, hemiplegia
4.	Other malignancies (except basal cell skin carcinoma)
5.	Hypertension
6.	Diabetes mellitus (medically treated)
7.	Other: Soft tissue diseases (Besnier Boeck disease (sarcoidosis), Wegener's granulomatosis, SLE (systemic lupus erythematosus) Rheumatoid arthritis (only severe) Kidney diseases (chronic glomerulonephritis, chronic pyelonephritis) Bowel diseases (Crohn's disease, ulcerative colitis) Liver diseases (cirrhosis, hepatitis) Dementia Tuberculosis

Current line of treatment

Whether a patient is receiving first, second or third line treatment for their lung cancer is an additional indicator of the duration and extent of their disease. I defined first line treatment as the initial therapy received following a diagnosis of lung cancer. Second line treatment was defined as the treatment offered if or when the disease had failed to respond to initial treatment, or on recurrence of the disease. Finally, I classified third line treatment as the therapy given to patients on the failure of second line treatment, or following the second recurrence of disease.

Gender

As the NICE Guidance on Supportive and Palliative Care states, the palliative care needs of patients should be assessed and addressed regardless of a patient's gender (¹⁹ p.26). I therefore included gender as an explanatory variable, although at present there is no research evidence linking this to use of SPC.

Living alone

My ethnographic findings suggested the possibility that patients living alone, and patients with young children, may be given a higher priority to receive SPC. I therefore asked participants how many other adults and children (<18 years of age) they resided with. However, whilst I anticipated a sufficient proportion of respondents may be living alone to enable this variable to be included within analyses, I was less certain that this would be the case for the proportion with children.

Deprivation

Deprivation, measured at both an individual and an area level, is associated with variations in use of a wide spectrum of health care services.⁴⁶⁰ Socio-economic deprivation has been associated with lower rates of treatment, and subsequently higher mortality rates, in lung cancer.⁴⁶¹ Research on the influence of deprivation on end-of-life care has primarily focussed on variations in place of death, with lower home death rates in more deprived areas.⁴⁶² To capture any influence of deprivation on variations in use of SPC, I included this as a potential explanatory factor.

I assigned deprivation level to patients using the Index of Multiple Deprivation (IMD) 2004.⁴⁶³ This is a widely used indicator of deprivation within public health and health services research at both area and individual level, including studies on use of services by lung cancer patients.²⁴⁷ The IMD is a summary measure of area level deprivation comprising weighted scores in seven deprivation domains (income, employment, health and disability, education, skills and training, barriers to housing and services, crime, and living environment). IMD data are available at the Super Output Area (SOA) lower layer, covering a mean of 1500 people (minimum 1000).

There are 32,482 SOAs in England; each is assigned a score and rank for the total IMD 2004, as well as for the more detailed Domain Indices.

Whilst using area-level data applied to individuals always risks ecological fallacy (the assumption that individuals have the same level of deprivation as that assigned to the area in which they live), there is some evidence that individual and area level deprivation measures correlate well.⁴⁶⁴ I considered obtaining data on individual-level socioeconomic data using the National Statistics socio-economic classification (NS-SEC), as used for all official statistics. However, I considered this to be problematic for two reasons. Firstly, the NS-SEC is primarily an occupation-based classification system. This may not be appropriate in a population of lung cancer patients who are predominantly retired or on long-term sick leave. Secondly, the NS-SEC requires a minimum of four detailed questions (compared to postcode alone for the IMD). This may considerably increase instrument length and resulting responder fatigue. As a result, I decided to use the IMD system.

To assign a deprivation level to each participant, I used the rank of total IMD score to place each Super Output Area in England within a deprivation tertile (high, moderate and low). I then used postcode of residence to identify the correct SOA for each participant. Based on their SOA, I then assigned a deprivation tertile to each participant.

Ethnicity

There is little evidence on the influence of ethnicity on use of SPC. However, due to widespread concerns about variations in use of primary and secondary care between ethnic groups, I included patients' ethnicity as a potential contributory factor in equity of use.^{465;466}

Carer stress

As previously discussed, my ethnographic study identified carer stress as a potential contributory factor in referrals to SPC. I therefore obtained a validated measure of carer psychological stress, the GHQ-12, from those carers attending clinic with patients.

Cancer clinic/hospital attending for treatment

Variations in models of care, service availability and personnel at the different participating lung cancer clinics may impact on the likelihood of being referred to SPC services. I therefore included the site at which patients were recruited (corresponding to the site they were currently attending for care and/or treatment) as an explanatory factor. I also noted the site at which patients were diagnosed. Diagnosing site could differ from the recruiting/treating site due to referrals between hospitals, and particularly between cancer units and the cancer centre.

Deteriorating condition

My ethnographic findings highlighted the importance of a patient's deteriorating condition in precipitating a need for SPC. The assessment of patients on referral to SPC, and throughout the provision of care to them, included whether the patient's condition was continuing to decline. Stable disease and stable symptoms were frequently a reason for deciding a patient no longer had a need for SPC. However, within the cross-sectional survey, particularly with the EORTC QLQ-C30 as a measure of need for care, it was not possible to assess this dimension. This HRQL instrument did not include an assessment of how patients were changing over time, and it was not possible to construct a robust measure of this from medical records. Thus, whilst it remains an important component of need for SPC, it was not assessed within this survey.

7.4 Study procedures

Further details of the conduct of the study are outlined below.

Data preparation

Prior to the start of data collection, I drew up a data management plan to guide data collection, entry, and checking.

Data entry

I entered data into an SPSS database following my attendance at every clinic. I used single data entry with verification of a sample of records in preference to double data entry.⁴⁶⁷ This approach has been shown to produce satisfactory levels of accuracy within the context of limited study resources.

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Data checking

Checks on data quality following completion of data collection are less effective than ensuring initial high quality data through careful collection techniques.⁴⁶⁹ However, it is nonetheless essential to assess the nature and extent of inaccuracies arising from typographical and data extraction errors which may occur. Entering data immediately following every clinic meant I was able to swiftly resolve obvious data extraction errors, as participants' medical records were easily revisited in subsequent clinics for clarification. Following the completion of recruitment to the study, I conducted secondary checking of the data to assess the potential error rate, and to correct a proportion of the data entry errors. This involved a sequence of four different checks, each applied to the entire data set (including both patient and carer records):

1. Visual verification checks
2. Duplication checks
3. Range checks
4. Consistency checks

Data checking: visual verification checks

I carried out initial visual record verification checks on a random 10% sample of cases by comparing every variable in the selected records with the original questionnaires and data extraction forms. I generated samples using the 'select cases' function in SPSS; 30 cases from the patient database, and 21 from the carer database were highlighted for checking in this way. I corrected any discrepancies on the database to match the data as recorded on the questionnaire and data extraction form. I kept an error log using an Excel spreadsheet to record the number of errors per record, the nature of the error, and the correction made.

Out of the 30 patient records checked, I found a total of 8 typographical errors across 4680 entries (0.18% of entries). Three of these errors related to dichotomous variables, two to variables with more than 2 categories, and two errors involved dates. Out of the 21 carer records checked, I found a total of 6 typographical errors across 924 entries (0.65%). Four of these errors related to the same two, linked variables, with the wrong category value entered on each. One error was on a dichotomous variable (female gender was entered instead of male), and one related to a date. With a low proportion of errors (overall figures of greater than 0.5% have been commonly reported ^{467;468}) further visual verification checks were not conducted.

Data checking: duplication checks.

To ensure no records had the same unique identification number, I checked the frequency of ID codes. Two records were found to have the same ID number. On reference back to the original records, these were found to relate to two different patients. The ID code of one participant was amended, and all records updated.

Data checking: range checks.

To look for values falling outside of the expected range, I systematically examined the distribution of each variable using frequency tables. For categorical variables, I checked all observations to ensure they related to the permitted categories. For continuous variables, I performed frequency counts to ensure values fell within the expected range. Values which fell outside the permitted or likely range were checked against the original data collection sheets and amendments made as necessary. To record the range checks conducted, I created a table in Word listing every variable, its type (categorical or continuous), its permitted distribution (for categorical) or expected range (for continuous), the number of records for each variable, and, for errors, the number, nature and any corrections made. In checking the patient data, a total of two typographical errors were found across 97 variables, both relating to categorical data. I amended these on the database. In checking the carer data, no errors were found across 28 variables.

Data checking: consistency checks

I conducted consistency checks to ensure key variables were consistent for each participant. There were no cross-clarification checks conducted outside of the completed patient HRQL instrument, as none of the other recorded variables were open to inconsistencies which required or necessitated

clarification. However, I assessed the quality of data derived from the EORTC instruments, as explained below.

The EORTC scoring manual does not include recommendations about investigating the coherence of responses within the instrument/s. However, within and between the QLQ-C30 and the LC13, responses to certain items can lead to logical inconsistencies. To investigate the potential quality of responses by individuals, I adapted the approach taken by the developers of the SF-36 quality of life instrument.⁴⁷⁰ The SF-36 Response Consistency Index (RCI) uses 15 internal consistency checks based on pairs of SF-36 items – such as a report of being able to ‘walk more than one mile’ but not be able to ‘walk one block’ – to evaluate response quality.⁴⁷¹ A value of 1 is assigned to each inconsistent response pair, and a value of 0 to each consistent response. These are then totalled to form an RCI score for each respondent ranging from 0 (excellent data quality) to 15 (poor data quality). Reference values provided for the SF-36 show that 90.3% (2234/2474) of respondents in the general US population had no inconsistent responses⁴⁷¹; however, a study in patients with laryngeal cancer found only 75% of respondents had no inconsistencies.⁴⁷²

Applying this approach to the EORTC QLQ-C30 and LC-13, I identified before data collection the following seven item pairs which could contain potentially inconsistent responses:

1. item 3 (taking a short walk) and item 2 (taking a long walk)
2. item 8 (short of breath) and item 33 (short of breath when rested)
3. item 8 (short of breath) and item 33 (short of breath when walked)
4. item 8 (short of breath) and item 33 (short of breath when climbed stairs)

5. item 40 (pain in chest) and item 9 (pain)
6. item 41 (pain in arm or shoulder) and item 9 (pain)
7. item 42 (pain in other parts of body) and item 9 (pain)

The identification of inconsistencies within these response pairs can not in itself lead to the conclusion that individual responses are of a poor quality. Inconsistencies may arise through random error alone. Alternatively, respondents may react differently and give an apparently conflicting answer to stand alone items (such as 'were you short of breath?') compared to a run of similar items (such as 'were you short of breath when you rested/walked/climbed stairs?'). However, by identifying response inconsistencies, we can estimate the level of potential problems with data quality, regardless of how these problems have arisen.

For these data, I identified apparently inconsistent responses for each item pair. I then assigned a score of one for each inconsistent response pair, and calculated the proportion of respondents with any inconsistent response pairs [Table 7.8].

Table 7.8 Analysis of inconsistent response pairs in EORTC instruments		
Item pair	Inconsistent answers	Number of respondents with inconsistent responses
A problem taking a short walk / A problem taking a long walk	A little / Not at all	0
	Quite a bit / Not at all	0
	Quite a bit / A little	0
	Very much / Not at all	0
	Very much / A little	0
	Very much / Quite a bit	0
Short of breath / Short of breath when resting	Not at all / A little	1
	Not at all / Quite a bit	0
	Not at all / Very much	0
	A little / Quite a bit	0
	A little / Very much	0
	Quite a bit / Very much	0
Short of breath / Short of breath when walking	Not at all / Quite a bit	0
	Not at all / Very much	0
	A little / Very much	1
Short of breath / Short of breath when climbing stairs	Not at all / Very much	0
Pain in chest / Pain	Quite a bit / Not at all	1
	Very much / Not at all	0
	Very much / A little	0
Pain in arm or shoulder / Pain	Quite a bit / Not at all	1
	Very much / Not at all	0
	Very much / A little	0
Pain elsewhere / Pain	Quite a bit / Not at all	6
	Very much / Not at all	1
	Very much / A little	2
Total		13

13 respondents (13/254 = 5.1%) had one inconsistent response pair; none had more than one. I could not conclude that these are attributable to random error alone, but the low proportion of inconsistent responses suggests that items were commonly answered in a logical and consistent manner.

Once data cleaning was complete, I re-examined the distribution of all variables to double-check for consistency and accuracy. I identified no further problems.

Data reduction, reclassification and scoring

Following completion of data checking to identify data inaccuracies, I undertook a process of data reduction and reclassification to prepare the database for analysis. A primary focus of this was to transfer qualitative variables on participants' treatment and disease status into quantitative variables suitable for descriptive analysis. This involved, for example, converting string data on comorbidities into coded variables on the nature of the comorbidity, and the number of comorbidities for each patient.

During this phase, I also scored data from the EORTC QLQ-C30, the LC13 and the GHQ-12. The EORTC QLQ-C30 has nine multi-item scales and six single-item measures; the EORTC QLQ-LC13 has one multi-item scale and nine single item measures. Scales are scored in the same manner. Firstly, the average of the items that contribute to the scale is estimated. This is known as the raw score. The raw score is then standardised using linear transformation; scores range from 0 to 100. A high score on the global quality of life scale and the functional scales represents high (good) levels of quality of life / functioning. By contrast, a high score on symptom scales represents a high (worse) level of symptoms. Missing data are dealt with in one of two ways. If at least half the items from a scale have been answered, the scale score is calculated as above, with missing items ignored. If less than half the items have been completed, the scale score is set to missing. All single-item measures are set to missing. The EORTC supplies the SPSS commands for scoring the QLQ-C30 and QLQ-LC13, including the suitable treatment of missing data. These were run as an SPSS syntax file to calculate the scores for each participant.

The GHQ-12, contained within the carers' questionnaire, uses a four-point response scale which can be scored in a variety of ways, although the

developers recommend the use of their original binary method.⁴⁷³ This approach assigns a score of 0 or 1 as follows:

- symptom present ‘not at all’ = 0,
- ‘same as usual’ = 0,
- ‘more than usual’ = 1, and
- ‘much more than usual’ = 1.

Appropriate threshold scores for the GHQ-12, used to determine ‘caseness’, are known to vary according to setting, ranging from 1/2 to 6/7 out of a total possible score of 12.⁴⁷⁴ In recent years, the use of stratum-specific likelihood ratios has been explored as an alternative to threshold values in the GHQ-12, although these do not assign caseness.^{475;476} For the purposes of this study, the threshold value was set conservatively at 3/4 to avoid false positives.⁴³⁸

Data confidentiality and storage

To safeguard the confidentiality of participants, I did not record patients' and carers' personal details (name and address) on any questionnaires. I allocated an identifier code to each participant as they entered the study, recorded on all study documents. I noted participant details and codes in a handwritten code book, kept in a locked fire-proof filing cabinet separate to and away from the storage location of data. I transferred data to a computer database at regular intervals during data collection. These data were stored on password protected computers.

Sample size

The aim of the analysis was to assess whether there were differences in use of SPC services between older (≥ 75) and younger (< 75) lung cancer outpatients, after controlling for need and other explanatory factors. The

most recent available data, from a survey of 913 bereaved carers of patients who died from cancer in 2003 and 2004, reported 60.0% of patients under 70 and 38.9% of patients over 70 used community SPC.⁴⁷⁷ Data for differences in use under and over 75 years of age were not available from this study, and therefore the sample size calculation had to be estimated from this slightly different age group categorisation. To detect a 20% difference in use of SPC services between under and over 75's, with 95% confidence and 80% power, I would have to recruit 192 patients (96 in each age group).

However, to ensure stable estimates in multivariable models, there should be a minimum of 10 of the rarer events being studied for each covariate in the model.^{478;479} The complete list of potential coefficients to be included in the analysis is shown in Table 7.9; it includes ten variables representing 14 coefficients.

Table 7.9 Proposed coefficients to be included in multivariable analysis			
Variable	Data source	Categories	Number of coefficients contributing to model
Age	Date of birth: Medical records	Under 75 / Over 75	1
Gender	Medical records	Male / Female	1
Ethnicity	Patient report	White / Non-white	1
Deprivation	Postcode: Medical records	Low / Medium / High	2
Lives alone	Patient report	Yes / No	1
Recruiting centre	n/a	1 / 2 / 3 / 4	3
Extent of disease	Medical records	No metastases / Metastases	1
Current treatment	Medical records	1st line / 2nd or 3rd line	1
Comorbidities	Medical records	None / One / Two or more	2
Need for SPC	Patient report	Continuous: EORTC QLQ-C30 global quality of life score	1
TOTAL	-	-	14

Therefore, a sample of 250 would include an estimated 100 uses of SPC (at the rarest rate of 40% use), meaning a maximum number of 10 coefficients in multiple logistic regression models; a sample of 350 would include an estimated 140 uses of SPC, and be able to support a maximum number of 14 coefficients in multiple logistic regression models. On the basis of this information, and with consideration of the time-consuming nature of data collection following the pilot study, it was decided to aim for a maximum sample of 250 patients. This would enable 10 coefficients to be used, to be chosen as a result of univariable analysis.

Statistical analysis

Once I had fully prepared the data, I transferred them to Stata for analysis (StataCorp. 2007. Statistical Software: Release 9.2. College Station, TX: Stata Corporation).

Descriptive analyses

Distributions of categorical variables were examined using relative frequencies, to consider the number of participants in each category, and the proportion of missing data. Ordinal variables (EORTC scores) were examined using frequency distributions as appropriate.

Explanatory variables were then examined in relation to the outcome variable. Categorical variables were tabulated against use of SPC, and the proportions of patients in each category using or not using SPC calculated. For EORTC scores, median scores and inter-quartile range by use of SPC were calculated.

Univariable analysis

The associations between explanatory variables and use of SPC were then examined using univariable logistic regression to calculate crude odds ratios. Table 7.10 has details of each variable examined, and the coding used for each category.

Table 7.10 Coding of key explanatory variables	
Variable	Coding
Age	Under 75 = 0 75 and over = 1
Gender	Male = 0 Female = 1
Deprivation	Least deprived = 0 Mid deprived = 1 Most deprived = 2
Living alone	No = 0 Yes = 1
Recruiting centre	Centre one = 0 Centre two = 1 Centre three = 2 Centre four = 3
Extent of disease	No metastases = 0 Metastases = 1
Current line of treatment	First line = 0 Second or third line = 1
Comorbidity	None = 0 One = 1 Two or more = 2
Need for SPC	Global quality of life score = continuous

Multivariable analysis

Multiple variable logistic regression was carried out to examine the adjusted associations between explanatory variables and use of SPC. To carry out robust analyses, the inclusion of up to 14 coefficients in a multiple logistic regression model requires there to be 140 events. The 14 coefficients chosen to be potentially included in the model prior to the commencement of data collection were based on existing literature, policy and the results of the ethnographic study conducted as a prelude to the survey. No interactions between variables were expected on the basis of prior knowledge, and thus interaction terms were not included in the coefficient list. To reduce the number of coefficients to be included within the model to the anticipated maximum of 10, univariable regression results were considered. All explanatory variables with a P value of greater than 0.5 were not taken forward into the multivariable analysis. A high value of 0.5 was chosen to

ensure I could be confident that no important association was missed in the multivariable analysis.

Backwards elimination was then used to build a parsimonious logistic regression model from the remaining variables. All remaining explanatory variables (with $P < 0.5$ at the univariable level) were placed in the model. The variable with the highest P-value was then removed, with the threshold value for removal set at $P > 0.05$. Elimination of variables continued until no more variables could be removed from the model. To assess whether the same model could be achieved using a different approach, forward selection procedures were used with the same set of variables. Likelihood Ratio Tests (LRT) were used to examine the statistical significance of the variables included within the full, compared to a reduced, model. ^(480 p. 313) Goodness of fit was assessed using the Hosmer-Lemeshow test. ^(481 p.140) It was not possible to undertake multi-level modelling to take account of the effect of the treating and diagnosing clinic due to sample size restrictions.

Exploratory analysis of dimensions of quality of life

Whilst global quality of life score was used as an indicator of need for SPC in the main analysis, it is useful to know which particular dimensions of global quality of life are associated with use of SPC. Such dimensions could not be included in our main analysis due to sample size constraints. Key functional and symptom scores were identified *a priori*, based on factors identified within the ethnographic study as contributing to need for SPC. These were:

- Physical functioning
- Role functioning
- Emotional functioning
- Social functioning

- Pain
- Nausea and vomiting
- Dyspnoea (measured using the more extensive LC-13 scale)
- Fatigue, and
- Appetite loss.

Univariable logistic regression analysis was used to examine the relationship between these specific functional and symptom scales and use of SPC. Multivariable analysis was anticipated to be constrained by multicollinearity; in this situation, two or more dimensions of quality of life are so highly correlated that false associations between the explanatory and outcome variables may be obtained.⁴⁸² A correlation matrix (Spearman's correlation coefficients r) was used to examine the degree of correlation between selected HRQL variables. The proportion of moderately ($r = 0.4$ to 0.7) and strongly ($r = 0.7$ to 0.9) correlated HRQL variable pairs was calculated. Weak pairwise correlation coefficients do not necessarily exclude multicollinearity in this situation, as collinearity may exist between three or more variables.⁴⁸² Therefore, multivariable regression analyses were limited to examining the effect of each HRQL variable in turn on use of SPC, controlling for other significant factors. As a result, models only included one HRQL variable at a time. All EORTC variables were assessed for lack of conformity to a linear gradient by fitting each as a quadratic term.

Exploratory analysis of impact of carer stress

To assess the association of carer stress with use of SPC, an exploratory analysis was carried out using data from the sub-section of patients for whom carer GHQ-12 scores were available. Univariable analysis considered whether GHQ-12 score, as a continuous or dichotomous (caseness or not) variable, was associated with use of SPC. These variables were then added to

the final regression model developed for the entire data set, to assess whether an association existed after controlling for other factors known to be associated with use.

7.5 Results

Recruitment

A total of 842 patients attended the four participating outpatient clinics during the study recruitment period. I screened all patients against the eligibility criteria. Figure 7.4 shows the outcome of this process: 307 patients (36.5%) were eligible to be approached to participate in the study during the recruitment period, and 535 (63.5%) were ineligible.

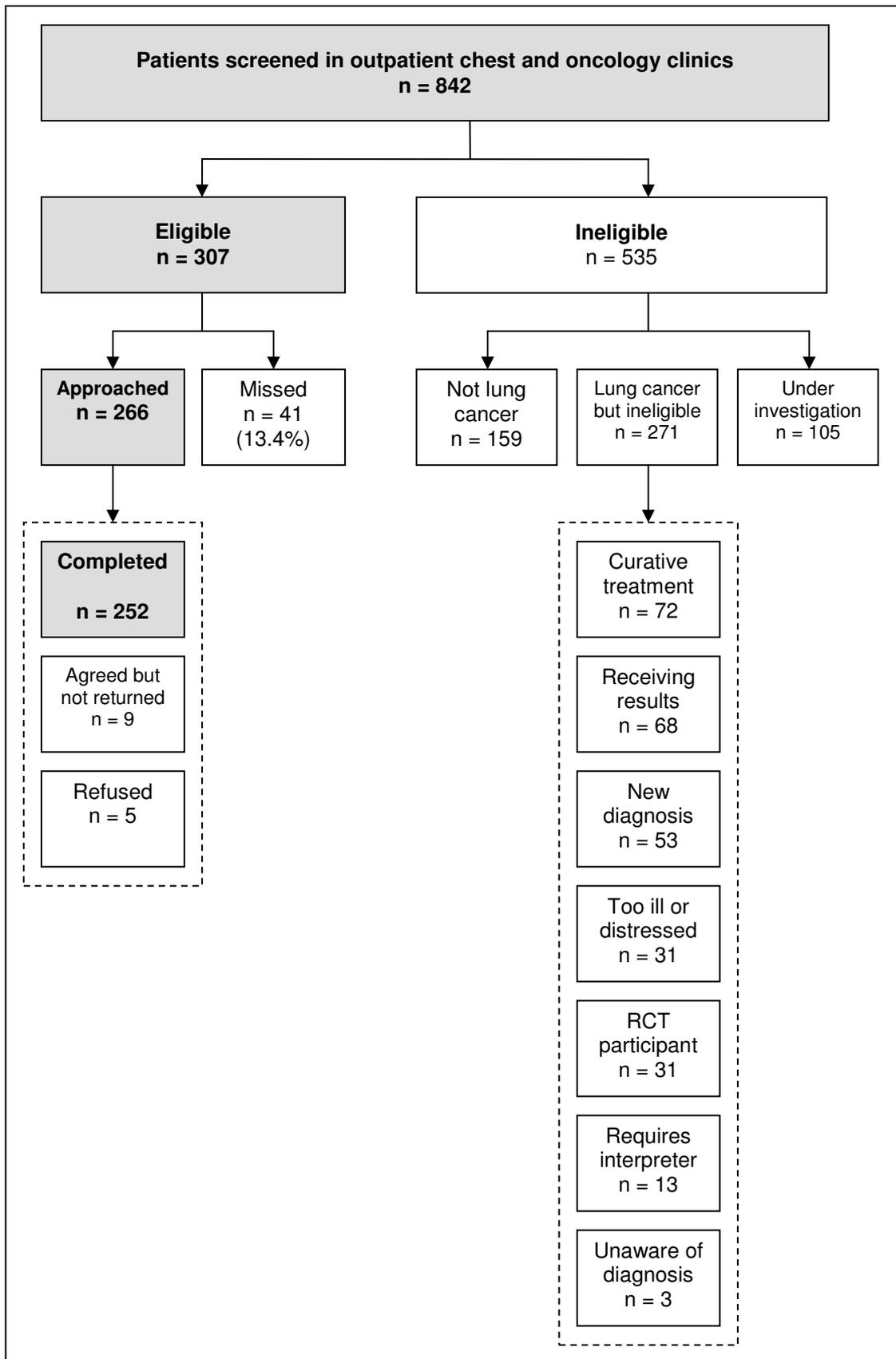


Figure 7.4 Eligibility of patients – screening of outpatient chest and oncology clinics

Of the 307 eligible patients, I approached 266 (87%) to introduce the study. I missed 41 patients as I was with other patients and unable to reach them before they left the clinic. Of those approached, 252 patients completed the study instruments (95% response rate), representing 82% of all eligible patients. Of those that did not complete the questionnaire, 9 stated they would prefer to post the completed study measures rather than completing them in the clinic but these were subsequently not received, and 5 declined participation in the study. An analysis of differences between responders and non-responders was not conducted. I did not have ethical permission to record data from the notes of non-responders or access any other source of information, so personal characteristics (such as age) were unknown.

Out of 535 ineligible patients, 159 (30%) did not have lung cancer, but were attending clinic for the assessment and treatment of conditions including COPD and other cancers. 105 patients (20%) had been referred for suspected lung cancer but were still undergoing assessment during the study recruitment period, and thus had not been diagnosed with lung cancer as yet. Finally, 271 patients (51%) did have a diagnosis of lung cancer but were not eligible to be approached about the study. The largest group of these (n=72, 27%) were receiving treatment with a curative intent, classified as surgery with or without adjuvant (radiotherapy or chemotherapy) treatment. 68 (25%) patients were attending clinic to receive results of investigations into the suspected progression of their disease, whilst 53 (20%) were attending clinic to receive their diagnoses of lung cancer, or for their first appointment to discuss treatment options following their diagnosis. The most diverse category were those lung cancer patients (n=31, 11% of ineligible patients) categorised as too ill or distressed to approach. This decision was taken in conjunction with clinic staff, and included patients with mental health or behavioural problems as well as those who attended

clinic requiring urgent medical attention (including patients in severe pain, those who were vomiting, and those who were judged to require immediate inpatient admission).

Of the 252 participants in the study, 178 (71%) attended clinic with at least one relative or friend [Figure 7.5]. Of these 178 carers, 4 were not asked to participate in the

study as clinic staff identified they had a degree of cognitive impairment (all four were elderly spouses of patients). Of the remaining 174 carers, 137 (79%)

participated in the study. Seven carers (4%) approached about the study declined to participate, three of these stating that

they did not feel it was relevant as they were a friend rather

than a family member. The remaining 30 (17%) who were approached took the questionnaire but did not complete the study instruments. This was usually because they assisted the patient with completing their questionnaire, and subsequently did not have time to complete the carer

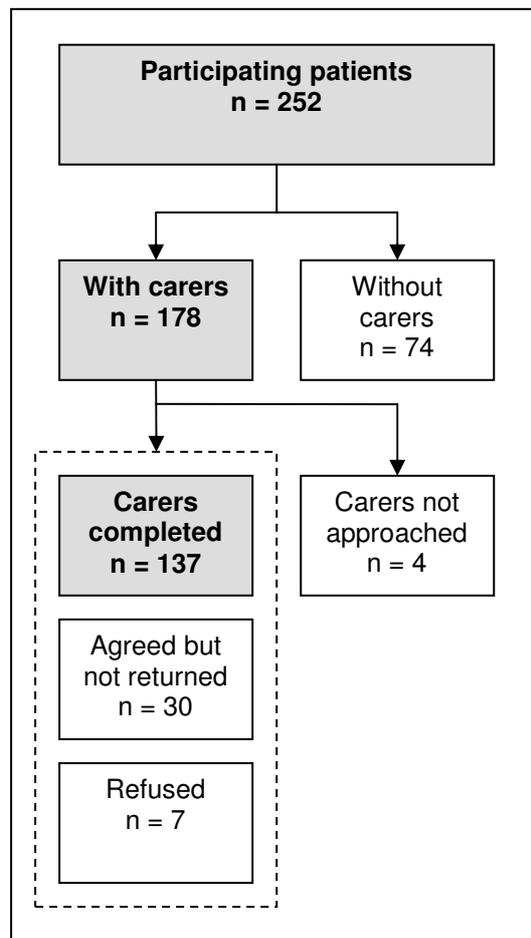


Figure 7.5
Recruitment of carers to study

questionnaire before they left the clinic; whilst as many as possible were requested to post the completed questionnaire back, none were received from this group.

Participating clinics contributed very different numbers of patients to the study [Figure 7.6]. Site one contributed 121 patients (48%), site two 93 (37%), site three 24 (10%) and site four 14 patients (6%). This reflected differences in the numbers of patients attending each clinic.

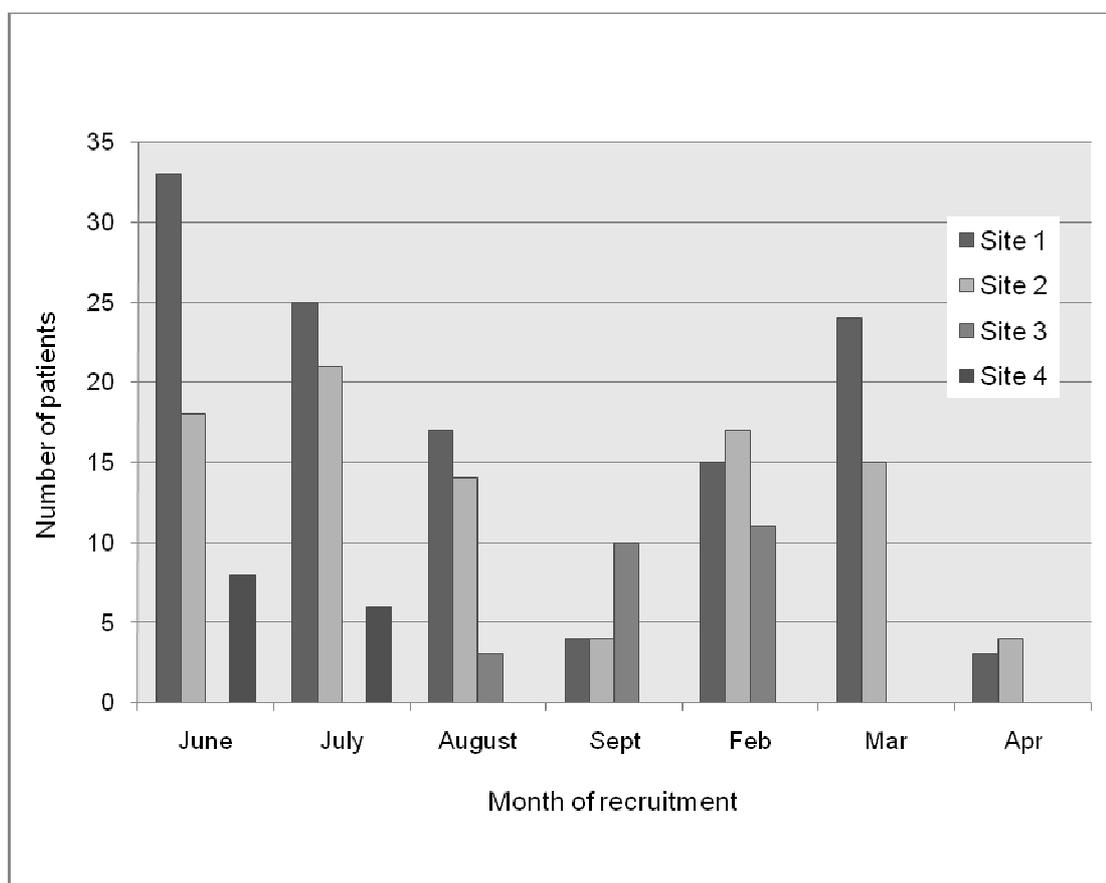


Figure 7.6 Patient recruitment to the study by month and clinic

Respondent characteristics

Socio-demographic characteristics: patients

Participating patients were aged from 42 to 92 years (mean age 69 (sd 9.9)) [Table 7.11]. Ethnicity was overwhelmingly white (95.2%); as a result of low numbers in non-white ethnic groups this variable was dropped from analyses. Additionally, only 5.2% of respondents (n=13) were living with children. This variable too was therefore not included in analyses.

Table 7.11 Respondent characteristics: patients	
Characteristic	n (%)
Age (years)	(n = 252)
< 55	26 (10.3)
55-64	55 (21.8)
65-74	95 (37.7)
≥ 75	76 (30.2)
Gender	(n = 252)
Male	139 (55.2)
Female	113 (44.8)
Ethnicity	(n = 251)
White	239 (95.2)
Black or Black British	8 (3.2)
Asian or Asian British	2 (0.8)
Mixed	1 (0.4)
Other	1 (0.4)
Marital status	(n = 251)
Married/living with partner	152 (60.6)
Divorced or separated	32 (12.8)
Widowed	53 (21.1)
Single	14 (5.6)
Social situation	
Lives alone	80 (31.8)
Children < 18 in household	13 (5.2)
Area-level deprivation (IMD 2004)	(n = 251)
Least deprived	47 (18.7)
Mid deprived	68 (27.1)
Most deprived	136 (54.2)

Compared to the age distribution of lung cancer incidence in England in 2004, patients age 75 and above were under-represented in the survey [Figure 7.7].⁴⁸³

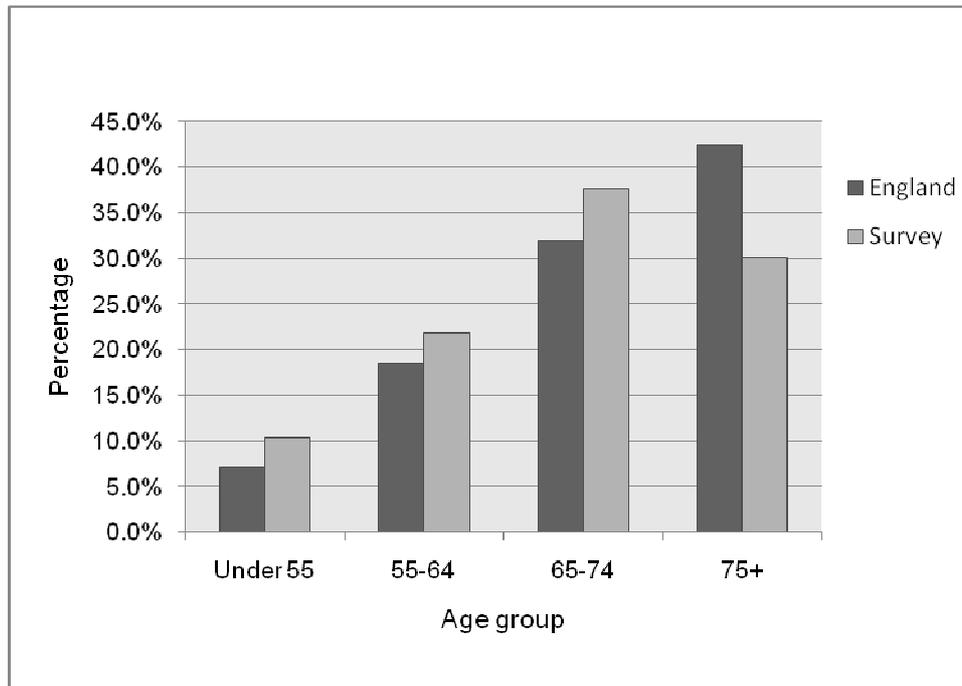


Figure 7.7 Age group of participating lung cancer patients compared to lung cancer incidence in England, 2004

Socio-demographic characteristics: carers

Of the 137 participating carers, the mean age was 54.7 (sd 12.9, range 19 to 83) [Table 7.12]. The majority (78%) were female; 51% were the spouse of the patient, and 36% the patient's son or daughter.

Table 7.12 Respondent characteristics: carers	
Characteristic	n (%)
Age (years)	(n = 135)
< 35	8 (5.9)
35-44	23 (17.0)
45-54	38 (28.2)
55-64	28 (20.7)
65-74	30 (22.2)
≥ 75	8 (5.9)
Gender	(n = 137)
Male	30 (21.9)
Female	107 (78.1)
Ethnicity	(n = 137)
White	135 (98.5)
Asian or Asian British	1 (0.7)
Mixed	1 (0.7)
Relationship to patient	(n = 136)
Husband/wife/partner	69 (50.7)
Son/daughter	49 (36.0)
Brother/sister	4 (2.9)
Other family member	10 (7.4)
Friend	3 (2.2)
Other	1 (0.7)

Clinical characteristics: patients

NSCLC was the most common type of lung cancer amongst participants (73.9%), compared to 24.5% with SCLC [Table 7.13]. Four participants did not receive a histological diagnosis and therefore the type of lung cancer remained unknown. These proportions reflect the proportions of lung cancer types in the UK, commonly accepted as being 75% NSCLC and 25% SCLC.

(²³⁹ p.63)

54.8% of participants had received their lung cancer diagnosis over six months ago. The median length of time between diagnosis and study participation was 7 months (inter-quartile range 3 to 19). Over half of participants (56.8%) had metastatic disease by the time of their participation

in the study. The most common metastatic site was another lung tumour, followed by bone and liver.

Table 7.13 Patient clinical characteristics	
Type of cancer	
SCLC	61 (24.5)
NSCLC	184 (73.9)
Not known	4 (1.6)
Stage of cancer at diagnosis	
NSCLC:	
Stage I	18 (10.3)
Stage II	12 (6.9)
Stage III	79 (45.4)
Stage IV	65 (37.4)
SCLC:	
Limited	17 (29.3)
Extensive	41 (70.7)
Time since diagnosis	
In the past month	13 (5.2)
In the past three months	61 (24.2)
In the past six months	40 (15.9)
More than six months ago	138 (54.8)
Metastatic disease at participation	
No	109 (43.3)
Yes	143 (56.8)
Site of metastatic disease *	
Other lung	58 (33.1)
Bone	35 (20.0)
Liver	31 (17.7)
Adrenal	22 (12.6)
Brain	20 (11.4)
Other	9 (5.1)

* Totals add up to more than 143 as 28 patients had metastatic disease at two sites, and two patients had metastatic disease at three sites

More than half (58.5%) of patients had relevant co-morbid disease recorded in their medical notes; of these, 90 (62.1%) had one additional disease, and 55 (37.9%) had two or more. The most-common comorbidity was hypertension (28.4%), but 15.3% of patients had been previously diagnosed with an

additional malignancy, and 20.9% had pulmonary disease including COPD [Figure 7.8].

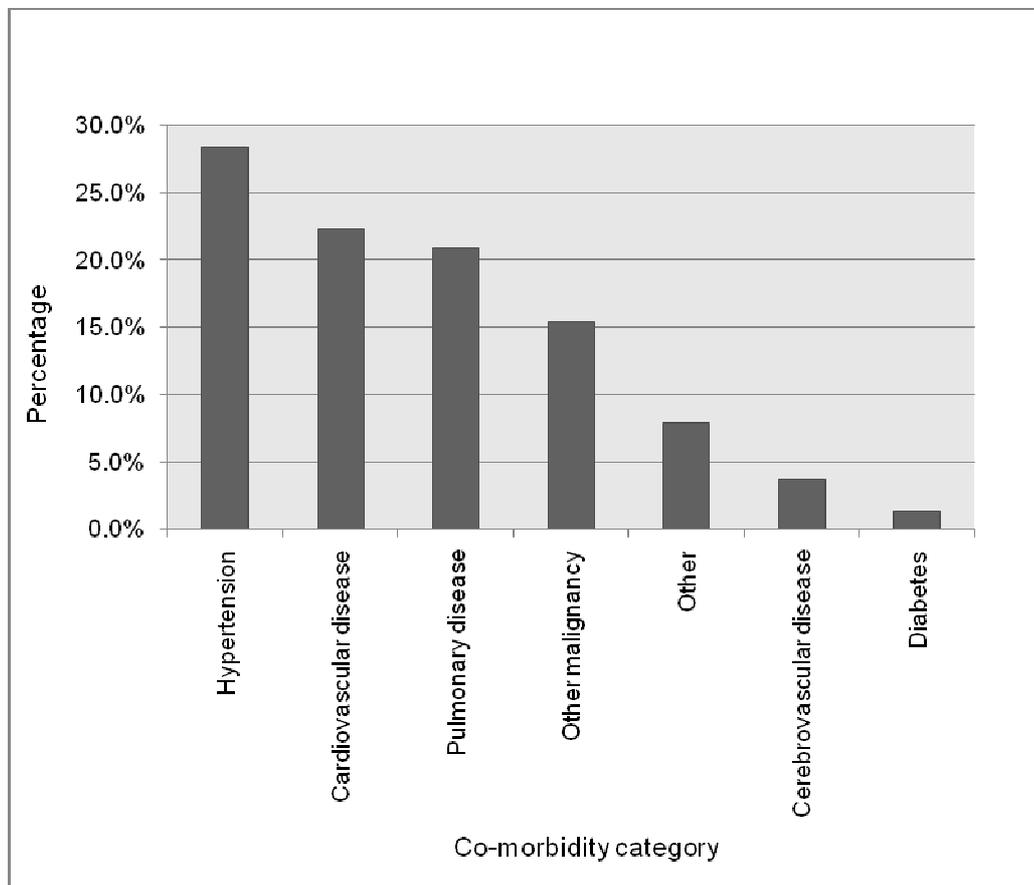


Figure 7.8 Prevalence of comorbidities

Treatment received

All but 3 participants had received treatment for their disease. 8.7% had received surgery prior to the recurrence of their lung cancer, 55.4% had received radiotherapy and 83.1% chemotherapy [Table 7.14]. At the time of participation in the study over half of participants were on follow-up after the completion of their most recent treatment.

Table 7.14 Treatment received	
Received surgery	
Yes	22 (8.7)
Lobectomy	17 (77.3)
Pneumonectomy	2 (9.1)
Wedge resection	3 (13.6)
No	230 (91.3)
Received radiotherapy	
Yes	138 (55.4)
No	111 (44.6)
Received chemotherapy	
Yes	207 (83.1)
No	14 (16.9)
Current or most recent treatment	
Chemotherapy	130 (53.5)
Chemotherapy & radical radiotherapy	24 (9.9)
Chemotherapy & palliative radiotherapy	57 (23.5)
Radical radiotherapy	5 (2.1)
Palliative radiotherapy	19 (7.8)
None	3 (1.2)
Other	5 (2.1)
Treatment status at participation	
On treatment	92 (38.0)
About to commence treatment	15 (6.2)
On watch and wait	132 (54.6)
No treatment received	3 (1.2)
Nature of current or most recent treatment	
First line	195 (81.3)
Second line	36 (15.0)
Third line	9 (3.8)

Quality of life

EORTC QLQ-C30 and LC13 scores revealed a high prevalence of symptoms. According to the raw scores, pain (a little to a lot) was reported by 64%; dyspnoea by 85%, fatigue by 91% and nausea by 35% [Figure 7.9].

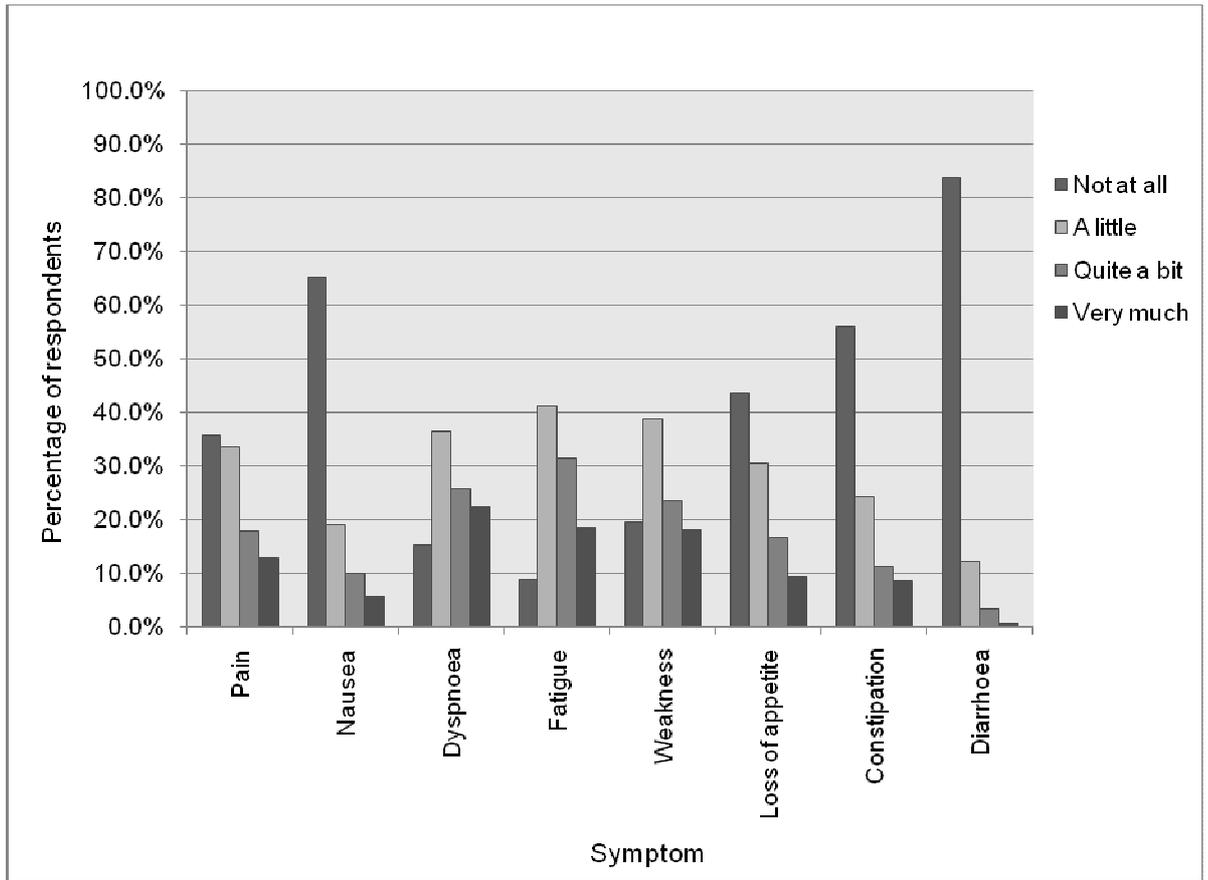


Figure 7.9 Raw QLQ-C30 scores for symptoms

Despite this high symptom burden, 65% of respondents rated their overall health as being average to excellent, and 69% felt their overall quality of life was average to excellent [Figure 7.10].

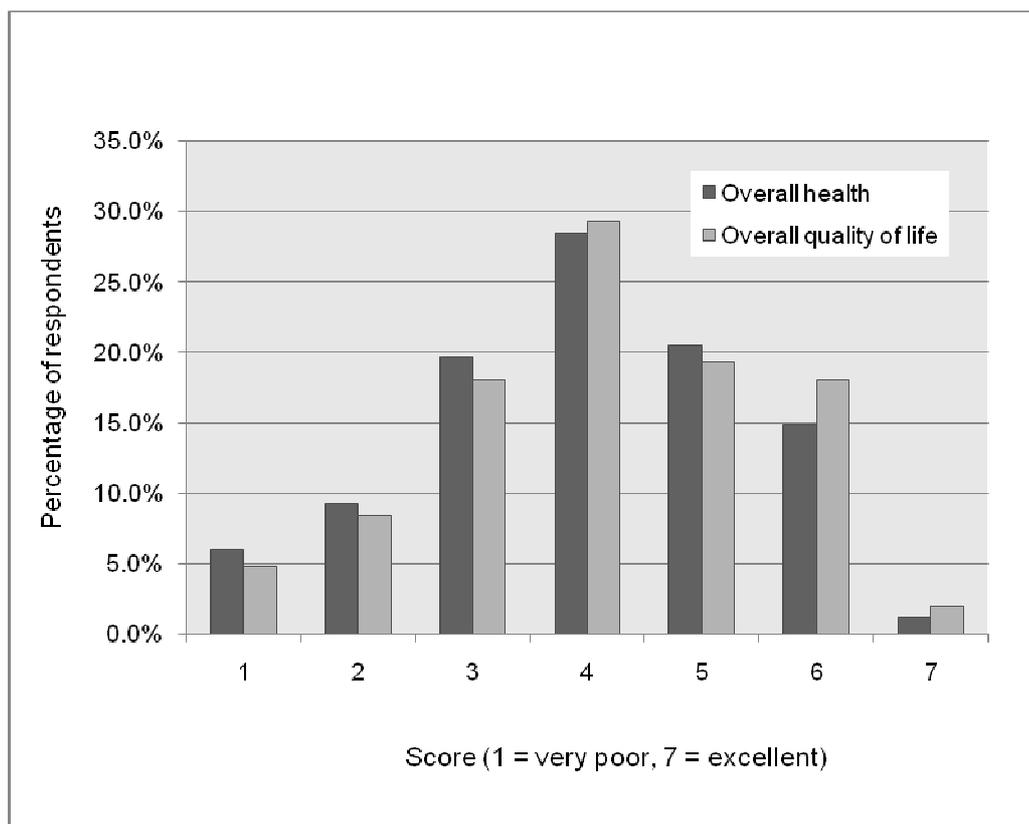


Figure 7.10 Raw QLQ-C30 scores for global health and quality of life

EORTC reference values are available by cancer site for transformed scores, enabling study samples to be compared against published data.⁴⁸⁴ I compared mean scores on key functional and symptom scales with reference values for NSCLC and SCLC populations. NSCLC reference values are derived from 794 patients recruited from Europe (including the UK) and Canada, 44% with local/locoregional disease and 56% with distant/recurrent disease. SCLC reference values are derived from 478 patients from Europe (including the UK) and Canada, 43% with limited disease and 57% with advanced disease.

Figures 7.11 and 7.12 show that mean symptom scores for the study sample closely follow those of the reference populations. NSCLC patients in the study have a slightly higher symptom burden than the reference population,

and SCLC patients a slightly lower burden. Mean functional scale scores, including global quality of life, also match closely between the study sample and the reference population [Figures 7.13 and 7.14].

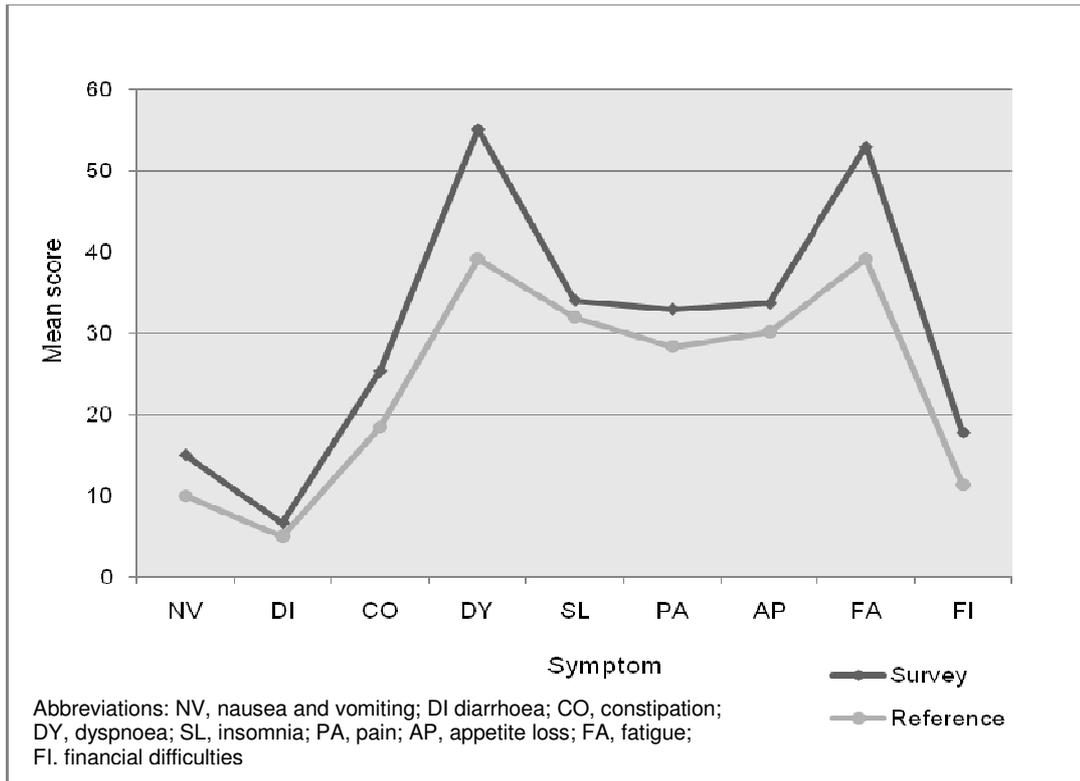


Figure 7.11 QLQ-C30 profiles: symptoms in NSCLC patients

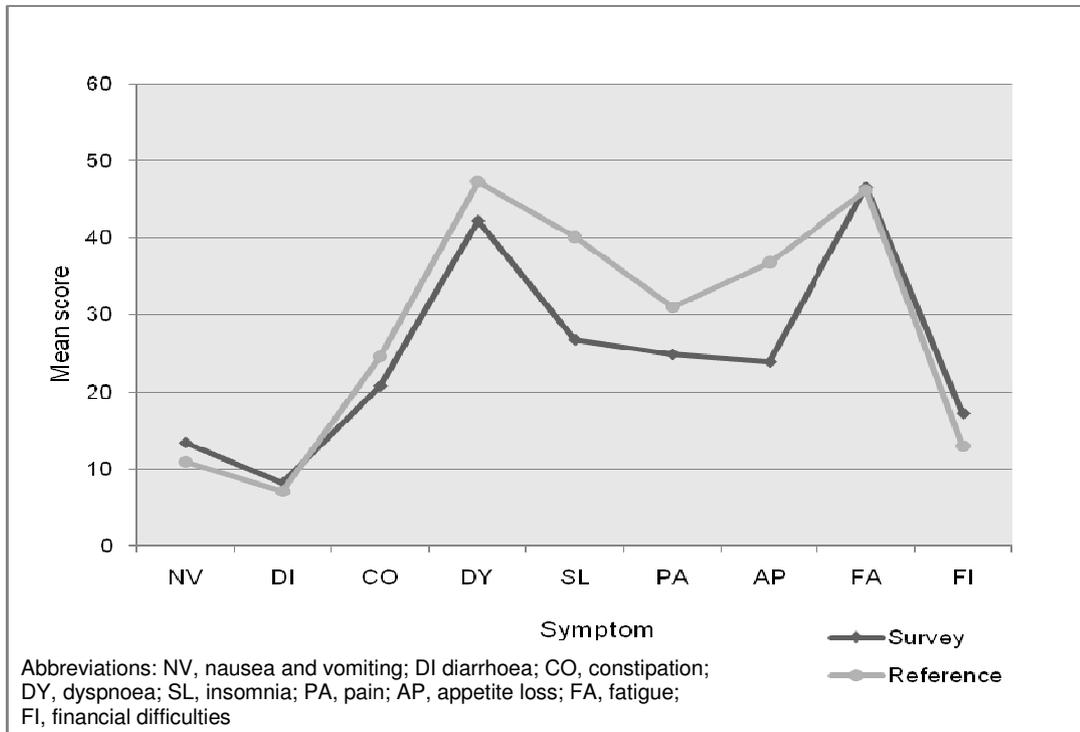


Figure 7.12 QLQ-C30 profiles: symptoms in SCLC patients

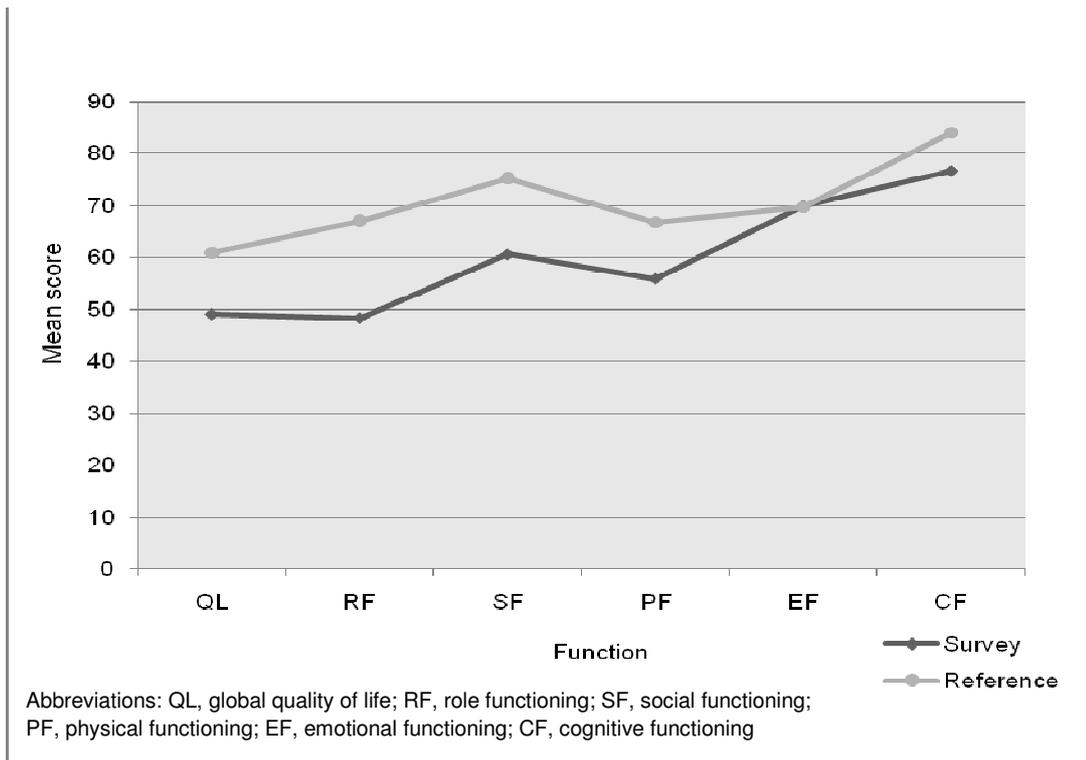


Figure 7.13 QLQ-C30 profiles: function in NSCLC patients

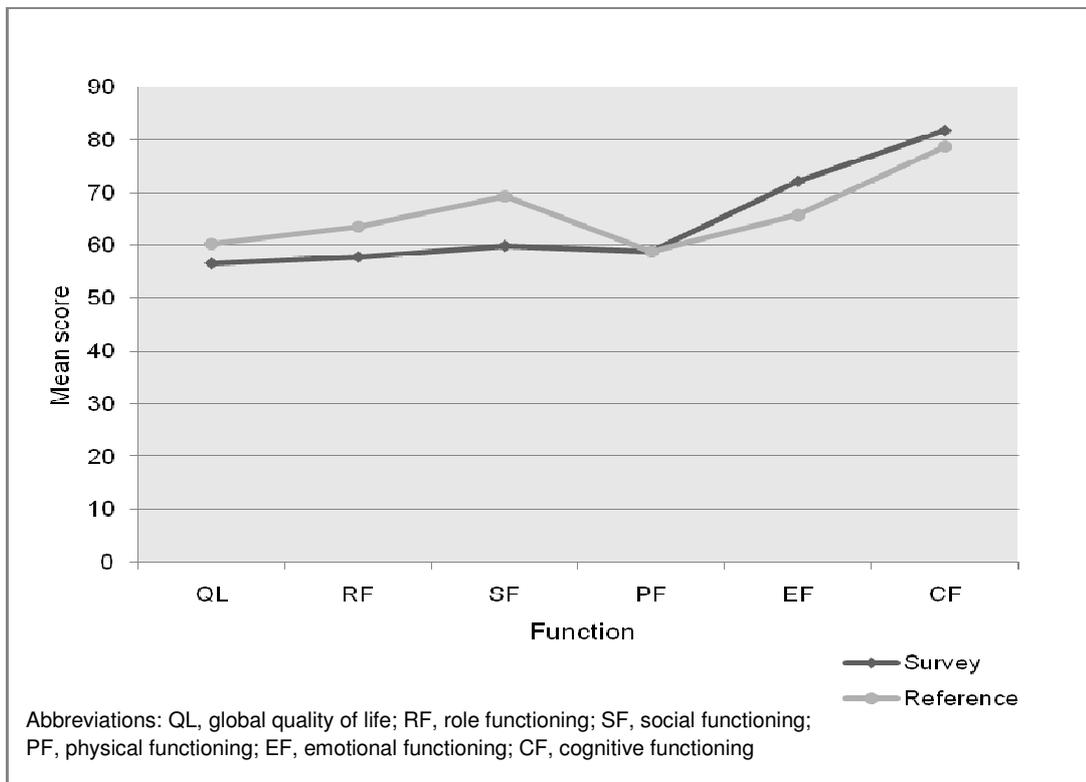


Figure 7.14 QLQ-C30 profiles: function in SCLC patients

Carer GHQ-12 scores

Figure 7.15 shows the distribution of GHQ-12 scores in family members and friends of participating patients (low (0) to high (12)). Using a threshold of 3/4 to determine psychological distress, 52% of carers (70/135: 46.7% of males and 53.3% of females) were cases. This is comparable to a study of 280 spouse carers of people with Alzheimer's disease, which found 58% were designated 'probable cases' using the GHQ-12.⁴⁸⁵ It is four times higher than the general population: data from the Health Survey for England, using the same threshold, reported that 11% of males and 15% of females had psychological distress.⁴⁸⁶

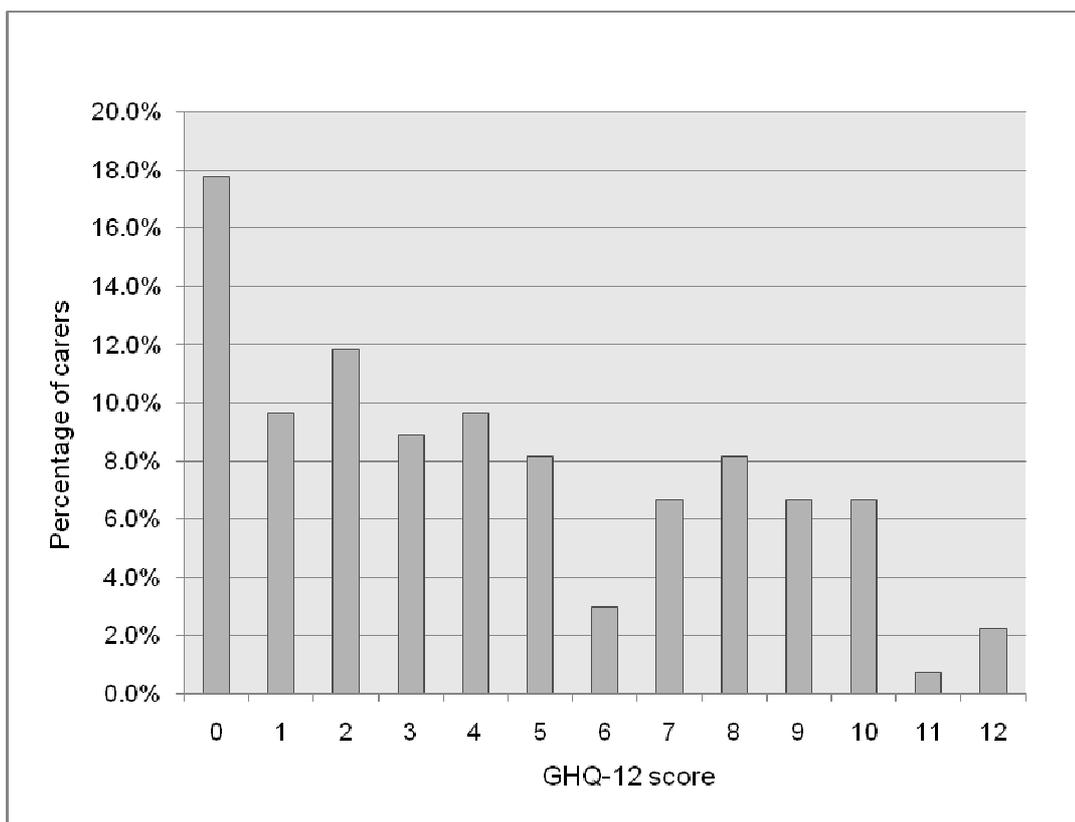


Figure 7.15 Carer GHQ-12 scores

Use of SPC

Confirmed use of SPC at the time of participation in the study, verified with local SPC services, was reported for 99 (39.3%) of participants. The median

time from diagnosis to referral to SPC for the 96 patients for whom referral date was available was 2 months (interquartile range 0.2 to 12 months) [Figure 7.16]. 22 patients (23%) were referred to SPC during the process of, or on the day of, diagnosis; all of these 22 patients had metastatic disease by the time they were diagnosed.

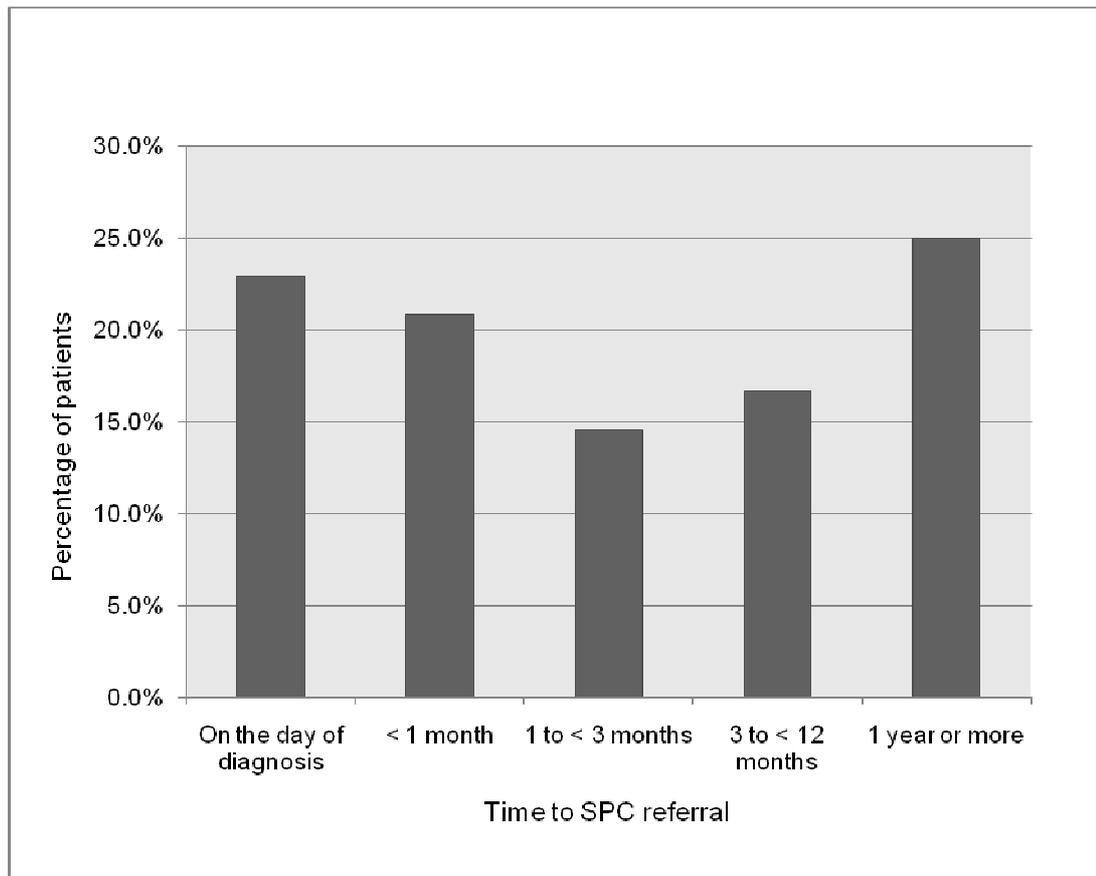


Figure 7.16 Time from diagnosis to SPC referral

Key explanatory variables were examined by use of SPC, using proportions or medians as appropriate [Tables 7.15 and 7.16]. A slightly lower proportion of older patients (75 or over) were receiving SPC compared to those aged under 75. There were large differences in use of SPC by treating clinic, with proportions of patients under SPC at each clinic ranging from 23.7% to 66.7%. When examined by diagnosing clinic, use of SPC ranged from 24.7% to 64.7%. Half of patients with metastatic disease (49.7%) were under SPC,

compared to 25.7% of patients without metastatic disease. Finally, 53.3% of patients on second or third line treatment were receiving SPC, compared to 36.9% of patients receiving their first treatment.

Median global quality of life score was 41.7 in users of SPC, indicating a lower perceived quality of life compared to non-users (median score 58.3). Lower scores were also observed in SPC patients for physical, role, emotional and social functioning. Users of SPC reported higher symptom burdens for fatigue, pain and dyspnoea.

Table 7.15 Use of SPC by demographic and disease variables		
	Use of SPC n (%)	
	Yes	No
Age		
Under 75	71 (40.6)	104 (59.4)
75 and over	28 (36.4)	49 (63.6)
Gender		
Male	48 (34.5)	91 (65.5)
Female	51 (45.1)	62 (54.9)
Deprivation		
Least deprived	17 (36.2)	30 (63.8)
Mid deprived	26 (38.2)	42 (61.8)
Most deprived	56 (41.2)	80 (58.8)
Living alone		
No	63 (36.6)	109 (63.4)
Yes	36 (45.0)	44 (55.0)
Treating clinic		
1	54 (44.6)	67 (55.4)
2	22 (23.7)	71 (76.3)
3	16 (66.7)	8 (33.3)
4	7 (50.0)	7 (50.0)
Metastatic disease		
No	28 (25.7)	81 (74.3)
Yes	71 (49.7)	72 (50.4)
Current/most recent treatment		
First line	72 (36.9)	123 (63.1)
Second or third line	24 (53.3)	21 (46.7)
Number of comorbidities		
None	42 (40.8)	61 (59.2)
One	33 (36.7)	57 (63.3)
Two or more	24 (43.6)	31 (56.4)

Table 7.16 Use of SPC by HRQL scores		
	Use of SPC [Median score (inter-quartile range)]	
	Yes	No
Global quality of life	41.7 (33.3 to 58.3) (n = 99)	58.3 (41.7 to 75.0) (n = 150)
Physical functioning	46.7 (26.7 to 73.3) (n = 99)	60.0 (46.7 to 80.0) (n = 153)
Role functioning	33.3 (0.0 to 66.7) (n = 98)	66.7 (33.3 to 100.0) (n = 149)
Emotional functioning	66.7 (41.7 to 91.7) (n = 99)	75.0 (66.7 to 100.0) (n = 150)
Social functioning	50.0 (16.7 to 83.3) (n = 99)	66.7 (33.3 to 100.0) (n = 150)
Fatigue	55.6 (33.3 to 77.8) (n = 99)	44.4 (33.3 to 66.7) (n = 150)
Nausea and vomiting	0.0 (0.0 to 33.3) (n = 98)	0.0 (0.0 to 16.7) (n = 151)
Pain	33.3 (16.7 to 66.7) (n = 99)	16.7 (0.0 to 33.3) (n = 1513)
Dyspnoea	44.4 (22.2 to 77.8) (n = 91)	33.3 (22.2 to 66.7) (n = 145)
Appetite loss	33.3 (0.0 to 66.7) (n = 96)	0.0 (0.0 to 33.3) (n = 150)

Regression analyses

Univariable logistic regression analysis found that the presence of metastatic disease, the treating clinic, the current or most recent line of treatment, and global quality of life score were significantly associated with use of SPC [Table 7.17]. Age (above/below 75) was not associated with use of SPC at a univariable level.

Table 7.17 Univariable regression analysis				
	OR	95% CI		P value
Age				
Under 75	1.00			
75 and over	0.84	0.48	1.46	0.53
Gender				
Male	1.00			
Female	1.56	0.94	2.60	0.09
Deprivation				
Least deprived	1.00			
Mid deprived	1.09	0.51	2.36	
Most deprived	1.24	0.62	2.45	0.81
Living alone				
No	1.00			
Yes	1.42	0.83	2.43	0.21
Treating clinic				
1	1.00			
2	0.38	0.21	0.70	
3	2.48	0.99	6.23	
4	1.24	0.41	3.75	<0.001
Metastatic disease				
No	1.00			
Yes	2.85	1.66	4.90	<0.001
Current/most recent treatment				
First line	1.00			
Second or third line	1.95	1.02	3.75	0.045
Number of comorbidities				
None	1.00			
One	0.84	0.47	1.50	
Two or more	1.12	0.58	2.18	0.69
Global quality of life				
One unit increase	0.97	0.96	0.99	<0.001

On the basis of the univariable analysis gender, living alone, treating clinic, metastases, line of treatment and global quality of life were entered into a logistic regression model. Following backwards elimination, the final model contained treating clinic, quality of life and metastatic disease [Table 7.18]. This was confirmed using stepwise forward regression. LRTs indicated that all were significantly associated with use of SPC after adjusting for the other

variables. Age (< 75 / ≥ 75 and as a continuous variable) remained not significant when forced into the final regression model. The Hosmer and Lemeshow's goodness-of-fit test for the final model gave a P-value of .84, showing that the model fits the data well.

Table 7.18 Final model for multivariable regression analysis				
	OR	95% CI		P value
Treating clinic				
1	1.00			
2	0.37	0.19	0.71	
3	2.43	0.90	6.52	
4	0.95	0.28	3.23	0.002
Metastatic disease				
No	1.00			
Yes	2.60	1.44	4.68	0.002
Global quality of life				
One unit increase	0.97	0.96	0.98	<0.001

Further analysis was undertaken to investigate whether the association of treating clinic with use of SPC was also to be found by diagnosing clinic. Diagnosing clinic was significant both in univariable logistic regression analysis (P = 0.0033) and in multivariable analysis with global quality of life and metastatic disease (P = 0.0052). The Hosmer and Lemeshow's goodness-of-fit test for this model gave a P-value of .99, indicating a good fit with the data.

Exploratory analysis of use of SPC in relation to HRQL variables

A correlation matrix for key HRQL variables found that over three-quarters (77.8%) of the correlations had an $r > 0.4$, with physical functioning, role functioning and fatigue having the greatest number of strong correlations [Table 7.19].

Table 7.19 Correlation matrix for selected EORTC QLQ-C30 and LC13 variables (absolute values of Spearman correlation coefficients, n = 228)									
	QL2	PF2	RF2	EF	SF	FA	NV	PA	AP
PF2	0.55								
RF2	0.58	0.75							
EF	0.45	0.48	0.45						
SF	0.48	0.50	0.56	0.53					
FA	-0.64	-0.74	-0.68	-0.57	-0.60				
NV	-0.31	-0.39	-0.30	-0.39	-0.37	0.44			
PA	-0.44	-0.54	-0.47	-0.51	-0.48	0.54	0.38		
AP	-0.45	-0.44	-0.40	-0.43	-0.37	0.54	0.55	0.41	
LCDY	-0.47	-0.61	-0.53	-0.44	-0.36	0.57	0.21	0.43	0.34

Abbreviations: QL2, global quality of life; PF2, physical functioning; RF2, role functioning; EF, emotional functioning; SF, social functioning; FA, fatigue; NV, nausea and vomiting; PA, pain; AP, appetite loss

Univariable logistic regression analysis found that physical, role, emotional and social functioning were all significantly associated with use of SPC [Table 7.20]. The physical symptoms of fatigue, pain, appetite loss were also all associated with use; nausea and vomiting was not, and dyspnoea was of borderline association. Pain and fatigue showed the strongest association with receiving care from a SPC team, along with physical and role functioning. Adding treating clinic and metastatic disease into the regression model for each HRQL variable made little difference to the associations; nausea and vomiting remained the one HRQL variable with no clear association with SPC, whilst the association between dyspnoea and use strengthened. All terms were fitted as linear effects.

Table 7.20 Exploratory regression analysis: use of SPC by key HRQL variables *								
	Univariable analysis			Multivariable analysis: treating clinic and metastatic disease included				
	OR	95% CI	P	OR	95% CI	P		
Physical functioning	0.98	0.97	0.99	<0.001	0.97	0.96	0.99	<0.001
Role functioning	0.98	0.98	0.99	<0.001	0.98	0.97	0.99	<0.001
Emotional functioning	0.98	0.97	0.99	0.001	0.98	0.97	0.99	<0.001
Social functioning	0.99	0.98	1.00	0.002	0.99	0.98	1.00	0.005
Fatigue	1.02	1.01	1.03	<0.001	1.02	1.01	1.03	<0.001
Nausea and vomiting	1.01	0.99	1.02	0.202	1.01	1.00	1.02	0.184
Pain	1.02	1.01	1.02	<0.001	1.02	1.01	1.03	<0.001
Dyspnoea	1.01	1.00	1.02	0.038	1.02	1.00	1.03	0.006
Loss of appetite	1.01	1.00	1.02	0.004	1.01	1.00	1.02	0.003

* All figures are reported for one unit increase in the variable of interest

Exploratory analysis of use of SPC in relation to carer distress

Further exploratory analyses were conducted on data from 131 patients whose carers had also participated in the study and had completed the GHQ-12 instrument. Of these patients, 39.9% (53/133) were under the care of a SPC team at the time of participating in the study. On a univariable level, neither GHQ-12 score as a continuous variable, or dichotomised into cases/not cases, were associated with use of SPC [Table 7.21]. Forcing GHQ-12 variables into the final regression model derived from the full data set did not alter the association.

Table 7.21 Exploratory regression analysis: use of SPC by carer GHQ-12 score								
	Univariable analysis				Multivariable analysis: treating clinic, metastatic disease and QL2 included			
	OR	95% CI		P	OR	95% CI		P
GHQ-12 score (0-12)								
One unit increase	0.99	0.90	1.10	0.900	1.00	0.89	1.13	0.953
GHQ-12 case (1=yes)								
No	1.00				1.00			
Yes	0.63	0.31	1.26	0.191	0.67	0.30	1.52	0.342

7.6 Discussion

I found no association between age and use of SPC. Receipt of such care was, however, associated with the presence of metastatic disease, global quality of life, and the treating cancer clinic. Exploratory analyses found that specific dimensions of quality of life, including both functional and symptom scales (for example, pain and fatigue) were also associated with use of SPC.

Participating lung cancer patients had a high overall symptom burden, with pain, dyspnoea and fatigue reported by the majority of participants. In half of the informal carers surveyed psychological distress was elevated, but this was not associated with use of SPC.

Limitations

This is the first time an investigation of SPC use has controlled for need using a psychometrically validated instrument. I was able to gather a wide range of potential explanatory factors directly from patients, and to confirm use of SPC with providers of care. Another important strength of this study was the high recruitment rate, with 82% of eligible patients taking part. This increases the likely generalisability of our results. I excluded a proportion of attending patients primarily as they were receiving results concerning disease progression, or required immediate medical attention. This could have resulted in recruitment of patients with less extensive disease or

symptoms. However, participants' EORTC scores were comparable to, or worse than, reference values for NSCLC and SCLC patients, suggesting that their symptoms and functional status were representative of lung cancer patients as a whole. I was not able to record characteristics, such as age, from patients excluded from the study, and was thus unable to undertake an analysis of the differences between responders and non-responders.

Due to the cross-sectional design, it was not possible to understand use of SPC within the context of patients' disease trajectories. In particular, I do not know whether older cancer patients were referred to services at a later stage than younger patients. The design also means I cannot identify causal relationships. Thus, whilst I found an association between global quality of life ('need') and use of SPC, I cannot conclude that lower quality of life precipitates a referral to SPC. For example, it may be metastatic disease that triggers clinicians to refer to SPC, and the association of quality of life with SPC use is in fact a reflection of the association of poorer quality of life with more advanced disease. Additionally, I did not examine the role of deterioration in determining need for SPC, although this was an important dimension of need within my ethnographic findings.

Patients were recruited from four lung cancer outpatient settings within one cancer network in London. Limited resources meant it was not possible to include an additional contrasting geographical area (such as a rural setting), and this may restrict the generalisability of the results to other locations. The inclusion of cancer units together with a cancer centre does, however, reflect the organisation of cancer services throughout England.

In addition, the outpatient setting excluded lung cancer patients following other diagnostic and treatment routes, who may have different patterns of

use of SPC. Referral guidelines recommend a common route of GP presentation, chest x-ray, and referral to a chest physician clinic following a positive result.²³⁷ These guidelines were the basis for choosing respiratory outpatient clinics as the setting for the study. However, diagnosis and treatment patterns are unlikely to be the same for all patients. A cohort study of 246 lung cancer patients in Exeter, Devon diagnosed between 1998 and 2002 found that, whilst 61% (n = 150) were referred by their GP for specialist investigation as outpatients, only 73% of these (n = 110) were referred to a respiratory physician.⁴⁸⁷ 23% (n = 56) were admitted to hospital as an emergency. Of the 210 patients referred to secondary care, 93 of these were before the publication of the NICE guidance on lung cancer, and 117 after. There were statistically significant differences in the route of referral following guidance publication, with 37% being referred to a respiratory physician before, and 64% afterwards. Whilst this is a substantial improvement, it remains likely that not all lung cancer patients are referred to designated lung cancer outpatient clinics.

Patients over 75 years were under-represented in the study sample. This has important implications for the generalisability of the results, and particularly the finding that age was not associated with use of SPC in the study sample. It may be attributable to the contribution of 48% of participants by the cancer centre, many of whom travel large distances to attend. More elderly patients may choose not to travel such distances to receive their care. In addition, older patients may be more likely to be treated as inpatients; to be cared for under different specialties including medicine for the elderly; or to be diagnosed (if at all) much later in the disease course and to remain outside the lung cancer clinic setting.⁴⁸⁸

Further, 95.2% of patient participants stated their ethnicity to be white. I was not therefore able to consider use of SPC in relation to ethnic group, due to the small numbers in non-white categories. Figures on cancer incidence in relation to ethnicity are sparse due to the under-recording of this variable: a survey by the Thames Cancer Registry of 2002 cancer registrations found that only 22.6% had a valid ethnic code. (⁴⁸⁹ p. 83) London Health Observatory data shows that in 2000/2001, the ethnicity of London residents admitted to hospital for lung cancer was unknown for 29% of males and 31% of females; of the remainder, 64% of males and 63% of females were reported to be white, and 6% of males and 5% of females from other ethnic groups. ⁴⁹⁰ The 2001 census reported 75.3% of area residents to be white. Taking these figures together, it is likely ethnic minority lung cancer patients are not attending outpatient clinics in sufficient numbers, with a proportion being diagnosed and treated in other settings.

Developing a rigorous and effective approach to the measurement of need was a major challenge for this study. As I discussed in Chapter 6, there are currently no psychometrically robust instruments with which to measure need for SPC within research. My choice and use of an existing HRQL instrument was guided by the aspiration of measuring provider-defined need. A number of limitations arise from this approach.

Firstly, I chose an existing HRQL instrument based on domains of need developed through my ethnographic study, as well as psychometric considerations of reliability and validity. The choice therefore represents only my interpretation of need for SPC. Others may have derived different categories of import and reach different conclusions. An alternative measure of need may lead to different conclusions on the presence or absence of equitable care. Whilst age was not associated with use of SPC at a

univariable level (even before controlling for need), this remains an important conceptual point.

Secondly, the balance between ensuring psychometric robustness and establishing content validity meant that I was limited in the choice of available instruments, and in how these instruments could be used within an analysis of equity. Of particular concern, the EORTC-QLQ-C30 and LC-13 do not enable the calculation of a total scale score to reflect the multiple domains covered by the instruments. Therefore, I used global quality of life score as an indicator of SPC need. It is thus possible that, in spite of my extensive critical appraisal of available instruments and their relevance to domains of need for SPC, my measure of SPC need was not sufficiently comprehensive. However, I did conduct further exploratory analyses to investigate the association of particular dimensions of need (including pain, breathlessness and fatigue) with SPC use.

Thirdly, due to time pressures relating to the requirements of gaining ethical approval, I was not able to assess providers' views on my choice of instrument. Seeking the perspectives of SPC staff on my analysis of the domains of need and their mapping onto available HRQL instruments would have considerably strengthened the foundation on which my choice of instrument was based.

Fourthly, I hoped that greater or lesser need as measured by the chosen HRQL instrument would reflect the prioritisation of patients by SPC providers. However, I did not investigate if patients' scores on the EORTC-QLQ C30 and LC13 reflected their prioritisation by SPC providers. This would be an interesting exercise in how the instrument relates to the decisions made by SPC providers.

Finally, in spite of my best efforts to match the chosen HRQL instrument with a conceptualisation of need, it is unlikely that I can measure or capture every effect that SPC has.

The final issue I wish to highlight is that this study confined itself to an assessment of horizontal equity, considering the association between quality of life ('need') and the presence or absence of SPC use. I did not collect data on intensity of use, covering the nature and level of contact each patient had with their SPC provider. Such data, together with a larger sample of patients, would enable a more detailed analysis of whether variations in need were associated with variations in use: for example, whether patients with a higher need for care received a greater level of input from SPC. An alternative approach would link stage of disease with the specific amount of SPC use, again to assess whether there was equal use of SPC at every level of need. Finally, consideration of vertical equity could also investigate the urgency with which patients are referred to SPC in response to quality of life or stage of disease, reflecting Mooney's conceptualisation of this concept as one of prioritisation.⁷¹ Whilst all of these approaches would considerably strengthen my examination of equity, the requirement for a much larger sample size and additional data on SPC use precluded this within the current study.

The findings in context

39.3% of participating patients were on the caseload of a local SPC service at the time of their completion of the study instruments. Comparable recent figures for use of SPC by cancer, and particularly lung cancer, patients are limited. A retrospective survey of relatives bereaved in 1990 found that 27.8% of cancer patients (all sites) were reported to have received SPC at some point up until their death.¹²⁴ A separate analysis of the same study

data reported 29% of lung cancer patients had received help from a palliative care nurse.²⁵² However, these figures are based on retrospective recall of relatives some months following death, and rely on the correct identification of palliative care professionals by respondents. In a survey of 50 NSCLC outpatients in one UK hospital in 2000, 30% reported receiving care from a Marie Curie nurse, Macmillan nurse or hospice centre, and 56% reported that they had been offered or were aware of these services.²⁵³ Such figures must be approached cautiously; in my pilot study I found patients tended to over-report SPC use compared to actual SPC use. In this study, usage at treating hospital sites ranged from 24% to 67%, a variation discussed in more detail later.

Participating patients in this study reported a wide range of difficulties, both functional and symptomatic. In a survey of cancer outpatient attendees across eight tumour groups (including breast, gastrointestinal, head and neck and brain), lung cancer patients were identified as having the highest number of symptoms, and the most severe problems.¹⁰⁶ In this study, 50% of those with metastatic disease were not receiving SPC, suggesting that in spite of the presence of advanced disease and corresponding symptom burden, SPC usage is not widespread.

Use in relation to age

This study set out to consider use of SPC in relation to age. A systematic review conducted as background to this work found that, in previous studies conducted both in the UK and elsewhere, crude odds ratios for the use of SPC in older (primarily 75 and above) versus younger cancer patients ranged from 0.33 (0.15–0.72) to 0.82 (0.80–0.84).¹⁵ The odds ratio for use of SPC in older (≥ 75) and younger (<75) patients in this study was 0.84 (0.48 to 1.46). Therefore, whilst there was a slightly lower use of SPC in older patients, the

confidence intervals were wide and I found no statistically significant difference. There are a number of possible explanations for the discrepancy in findings between the current study and previous research.

It is possible that the extensive reforms in cancer treatment and diagnosis from Calman Hine onwards have eliminated discriminatory practices within cancer clinics since the majority of previous studies were conducted. One of the consequences of the Calman-Hine cancer care reforms was an expansion in the numbers of palliative care consultants and nurses working as members of the lung cancer multidisciplinary team. This is likely to have raised the profile and understanding of SPC, and facilitated appropriate referrals to these services.⁴⁹¹

Additionally, studies based on retrospective report (as much previous research is) may have inaccurate outcomes figures which lead to false conclusions of inequalities in care. I found that patients tended to over-report use of SPC, perhaps due to confusion over the specific titles and roles of the doctors and nurses they saw during the course of treatment. As it is plausible that inaccuracies in such reports may vary with patient and carer age, this problem may become more acute in older respondents.

Further, it is possible that over-75s are under-represented within the outpatient clinic compared to the population incidence of lung cancer. Whilst the evidence on treatment pathways is sparse, older patients may be more likely to be treated as inpatients; to be cared for under different specialties including medicine for the elderly; or to be diagnosed (if at all) much later in the disease course and remain outside the lung cancer clinic setting.⁴⁸⁸ If this is the case, additional research is required to establish whether there is a difference in use of SPC by age and other important variables for patients

treated in settings other than lung cancer specific outpatient clinics. It would also be important to examine differences in use of SPC between those treated within the outpatient compared to other settings, particularly care of the elderly.

However, there are also a number of issues arising in the design and conduct of this study which may contribute to my findings.

Firstly, the possibility of an under-powered study must be considered. The study was powered to detect a difference in use of 20% between older (≥ 75) and younger (<75) age groups, however:

- only 76 (30.2%) of participants were aged 75 and over
- the achieved sample size was 252. A maximum of 300 was the ideal target to enable the inclusion of more coefficients within the regression analysis, although only 192 were required to locate the pre-specified difference in use
- the actual difference in use of SPC was 4.2%.

As already noted, the sample size calculation was based on the most recent English usage data available. This was derived from retrospective carer report concerning cancer deaths in 2003 and 2004: reported use of community SPC services was 60.0% in under-70s and 38.9% in 70s and over.

⁴⁷⁷ Alternative data sources on which to base calculations, located during the course of the background systematic review, were from older studies or other international contexts. ¹⁵ The review found widely varying differences in SPC use between age groups, which in part reflected different overall usage rates. For example, Italian data on use of home palliative care by cancer patients showed a difference in use of 3.3% between under and over

75s, although the overall usage rate across all ages was only 4.4%, perhaps reflecting differences in the health care system from the UK.¹²⁹ By comparison, in Canada (which has more similar system to the UK), one study found a difference in use of a palliative care programme between under and over 75s of 15.1%, in the context of a 44.2% overall usage rate.¹⁰²

On reflection, the choice of a 20% difference in use was perhaps over-optimistic. This difference was derived from a population-based survey including all types of cancer deaths, reporting use of SPC up until death. My setting was cancer-site specific, setting-specific (attendees of outpatient clinics) and included only living patients. This situation reflects the difficulties of fitting sample size calculations to available data sets where truly relevant data is lacking. The alternative of setting a minimal clinically important difference between age groups on which to base sample size calculations was considered, but such a figure would be subjective and difficult to defend.⁴⁹² To increase sample size, I would have had to extend the period of data collection, or extend the number of settings for data collection, neither of which were possible.

Secondly, previous figures for use of SPC by age are based on retrospective studies (cohort, proxy surveys and one case-control study).¹⁵ All were sampled from cancer deaths, and all therefore considered use of SPC up until the last weeks of life. The cross-sectional design of the current study precluded the inclusion of total SPC use. If differences in SPC use between older and younger age groups become more pronounced closer to death, with older patients less likely to receive such services at this point in time, this may explain the discrepancy between the findings of this cross-sectional study design with retrospective studies. However, such a hypothesis would require factors leading to higher SPC use in younger patients (such as age

discrimination) to become more influential in the period shortly before death. This seems unlikely.

Thirdly, it is possible that older people are not under-represented in the clinics, but were under-represented in the study. There is strong evidence that older cancer patients are less likely to receive active treatment for cancer, including lung cancer.^{247;454;493;494} Whilst I recruited from both chest and oncology clinics, there would be a reduced likelihood of recruiting patients attending chest clinics for six-monthly or twelve-monthly 'watch and wait' check-ups compared to patients attending oncology clinics every one to four weeks for treatment review. If older patients are more likely to be under 'watch and wait', it is possible that I missed a substantial proportion of such patients as they were simply not attending clinic as frequently as younger patients.

Finally, the choice of an age cut-off at 75 years may have influenced the result. It is possible that differences in use of SPC between older and younger patients in this sample do exist, but at an older age of 80 or 85. The choice of cut-off was made following careful review of the previous evidence on SPC use, and also with reference to the literature on definitions of old age. I felt a cut-off of 65 would be too 'young', especially as lung cancer is more usually diagnosed at an older age. Choosing an older age cut-off such as 85 would have resulted, in this current study, in too few participants in the older age group.

Use in relation to diagnosing and treating centre

I found that the hospital clinic within which patients were treated or diagnosed was an important determinant of SPC use. This suggests that a reduction in regional variations in access to care (a key aim of the Calman-

Hine reforms) has not been fully realised, at least in terms of access to SPC. Variation in the propensity of clinics to refer to SPC has been reported in the US health care system, where hospice enrolment for cancer patients varied from 50% to 80% between eleven participating health centres within one regional integrated health care system.¹³² Whilst evidence from the UK shows there are geographical variations in access to lung cancer treatment (surgery, radiotherapy or chemotherapy) according to health authority region,⁴⁹⁵ no other research has focussed on within regional differences in access to care, including palliative care.

There are a number of factors which may explain variations in SPC use within the network. The propensity of clinics to refer to SPC may be dependent upon individual clinic staff's attitudes towards and knowledge of SPC; the skills and availability of lung nurse specialists; and the integration of the clinic with local SPC services.⁴⁹⁶ The clinics studied differed in their staff composition and skill-mix: thus, the presence of a lung nurse specialist with a palliative care background in one cancer unit may explain the lower proportion of palliative care referrals compared to a clinic without a lung nurse specialist available to support patients. Additionally, there were indications that differences in perceived availability of SPC between clinics (for example, known staffing problems within local SPC services, or poor provision within the local area) may impact on the likelihood of referrals. Staff at the cancer centre in particular may have poorer links with palliative care services within the diverse geographical areas patients may be referred from, and there may be confusion over whose responsibility (the treating centre's or the diagnosing unit's) it is to refer patients for care. An emphasis on aggressive treatment within a clinic may lead to a lower level of consideration of palliative care. Differences in the perceived availability of SPC between clinics (for example, if there are known staffing problems

within local SPC services, or poor provision within the local area) may impact on the likelihood of referrals. There may also be differences in the care offered by local SPC services; some may be more likely to discharge patients from their care after a brief intervention, or decline to accept referrals.

Use in relation to metastatic disease

Given the emphasis of palliative care on care of patients with advanced, progressive illness, the association between metastatic disease and receipt of such services is to be expected.²⁷ SPC in particular focuses on those with complex and persistent problems which a generalist palliative care approach may not be able to deal with.¹⁹ Advanced disease is typically associated with an increase in symptom burden.²⁴⁰ As treatment options become more limited in the presence of metastatic disease, and the focus switches to control of symptoms rather than regression of disease, the consideration of referral to palliative care may become more pronounced. It is possible that the association between HRQL ('need') and SPC use, discussed below, may in fact reflect the association between HRQL and metastatic disease, and subsequently metastatic disease and SPC use, rather than quality of life in itself precipitating a referral to SPC. Alternatively, health care professionals may routinely perceive patients with advanced disease as having a greater need for SPC, regardless of their actual symptom burden.

Use in relation to health-related quality of life

Need for SPC was measured using a HRQL instrument, chosen following work in earlier phases on the conceptualisation of need and the most effective approach to measuring this. The primary indicator of need used was global quality of life measured using the EORTC QLQ-C30, an established and well-validated instrument used widely in cancer research.⁴⁹⁷

This measure, and by proxy need for SPC, was strongly associated with use; the odds of use increased as quality of life declined. The two items comprising the global quality of life scale ask respondents to rate their overall health, and their overall quality of life. Thus, half of the scale is focused on health, which may be interpreted as predominantly physical health. Its association with SPC use therefore reinforces the primacy of the physical domains of need for care.

Specific dimensions of quality of life (physical functioning, role functioning, emotional functioning, social functioning, fatigue, pain, and loss of appetite) were also strongly associated with use at a univariable level, with lower functional status and higher symptom burdens associated with an increase in odds of use. Pain and fatigue, the two symptoms most strongly associated with SPC use, have previously been identified as the most distressing symptoms for lung cancer patients.²⁴¹ It is possible that nausea and vomiting among the sample was primarily induced by chemotherapy, rather than being associated with more advanced disease and subsequent use of SPC. It was not possible to fully examine the inter-relationships between palliative care use and functional and symptom scales due to multicollinearity.

The aim of SPC is to achieve the highest possible quality of life for patients with progressive illness. One consideration at the beginning of this study was that patients receiving SPC may therefore have a better reported quality of life than patients not receiving such treatment, as a result of improved access to effective symptom control and psychological support. This was not the case. Higher symptom burden and poorer functional status indicated patients were more likely to be under SPC. However, this does not necessarily reflect ineffective care. It is possible that the poorer quality of life associated with use of SPC does improve on receipt of such services, but

remains below that of patients not referred to (and thus deemed as not needing) the service.

Summary and interpretation of findings

My results are to some extent encouraging, suggesting that extent of patients' disease and quality of life, rather than sociodemographic characteristics such as age, are associated with use of SPC within the specialist cancer care setting. However, outstanding questions remain to be resolved. The pathway to care for patients of all ages must be examined to determine whether these findings apply to patients treated in settings other than the specialist cancer care system, such as care of the elderly. The wide variation in use of SPC between clinics also requires further exploration, including the extent to which differences in clinic culture, provider relationships and service availability influence access to SPC.

This survey has demonstrated the feasibility of gathering data directly from patients, rather than relying on retrospective approaches, in examining equity of use of SPC. It further emphasises the importance of including a measure of need to investigate use. However, future research must be broader in scope to include all patients regardless of their treatment setting to better examine the use of services in relation to need.

This was the final phase of empirical work I undertook. In the concluding chapter which follows, I draw together findings from the qualitative and quantitative phases of this mixed methods study to present my inferences on need for and use of SPC. I return to the underlying themes of social justice and equity to consider how these results may be interpreted in the light of theories of inequalities in health care. Finally, I consider what further studies

may be required to continue to develop methodology, research and practice in this field.

Chapter 8

Conclusions

*Below the surface stream, shallow and light,
Of what we say we feel – below the stream,
As light, of what we think we feel – there flows
With noiseless current strong, obscure and deep,
The central stream of what we feel indeed.*

Matthew Arnold. Untitled. ⁴⁹⁸

In this study I investigated equity of use of SPC services by age within one cancer network. I had three core objectives:

1. To explore, using documentary evidence, qualitative observation and interviews, how SPC providers define and conceptualise patients' need for care.
2. To systematically identify HRQL instruments developed for use in palliative care and lung cancer patient populations, and to appraise their validity for use as indicators of need for SPC.
3. To conduct a cross-sectional survey to measure use of SPC in younger versus older lung cancer patients in relation to need.

In this chapter, I draw together findings from the different phases of work to present an integrated interpretation of results. I consider strengths and weaknesses in both the conception and implementation of the study. I reflect on how inferences drawn from the study relate to theories of social justice,

equity and need discussed earlier in the thesis, and consider methodological implications for investigations in this field. Finally, I present further questions raised by this work, and discuss their potential for future research and policy.

8.1 Integration of findings

The mixed methods design of this study was conceived to enable each phase of work to influence subsequent phases. Thus, I used findings from the ethnographic study to inform the design of the cross-sectional survey; to guide a choice of HRQL instrument as an indicator of need for SPC; to highlight variables to include in the primary analysis of the use of SPC; and to decide on further variables to include in exploratory analyses of the use of SPC in relation to specific dimensions of need. These inter-relationships between different aspects of the research are illustrated in Figure 8.1.

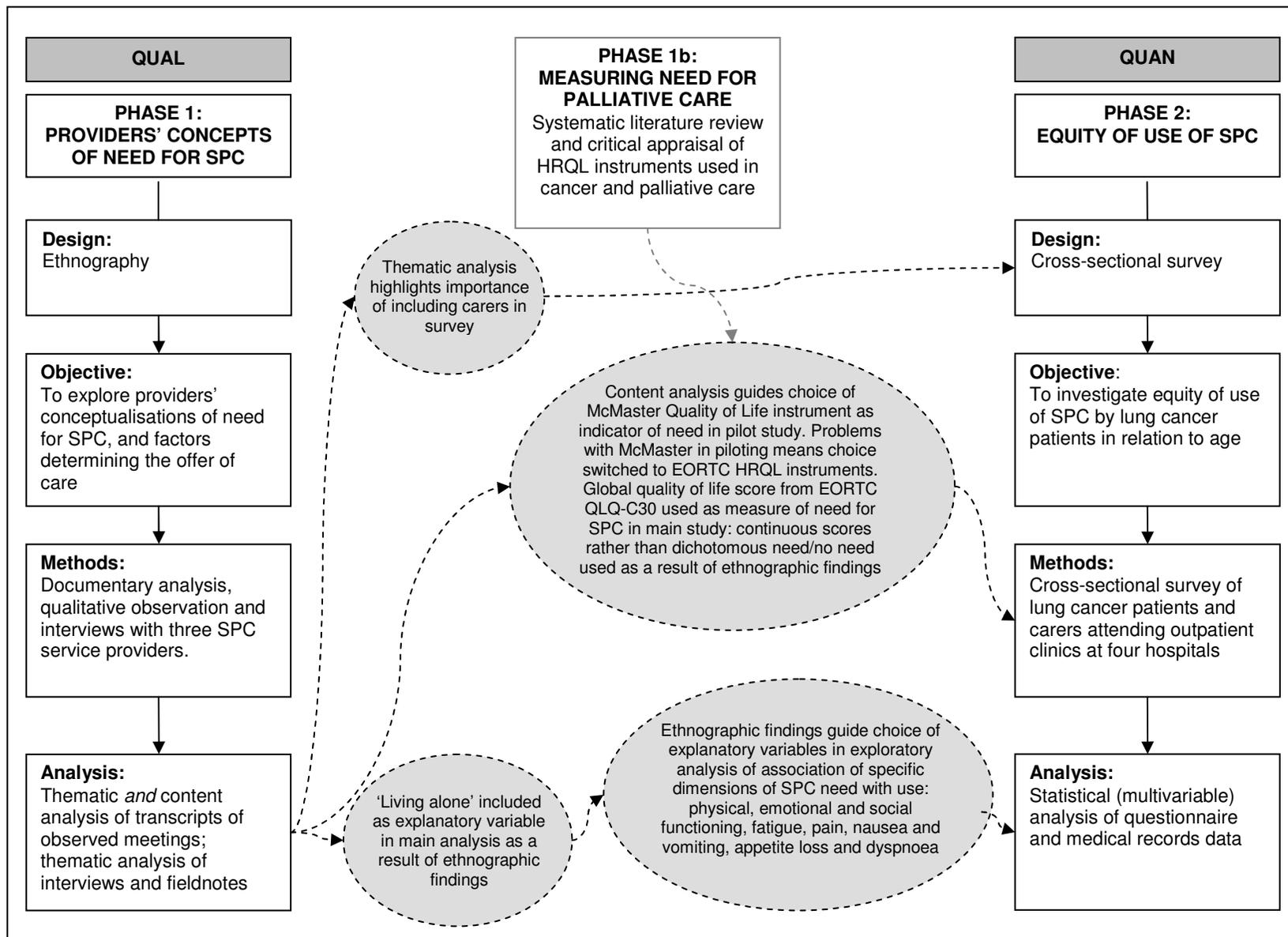


Figure 8.1 Study inter-relationships

My findings suggest that older age is not a barrier to the receipt of SPC for patients who are attending specialist cancer care clinics. Instead, the likelihood of referral to SPC for such lung cancer patients is associated with HRQL and disease severity [Figure 8.2]. In spite of a substantial proportion of carers reporting psychological distress, this is not associated with use of SPC. Whilst these findings demonstrate that referrals to SPC tend to respond to patients' symptoms and disease stage, wide variations in the proportions of patients using SPC between clinics suggest an important role for clinic culture and individual staff practice in determining access.

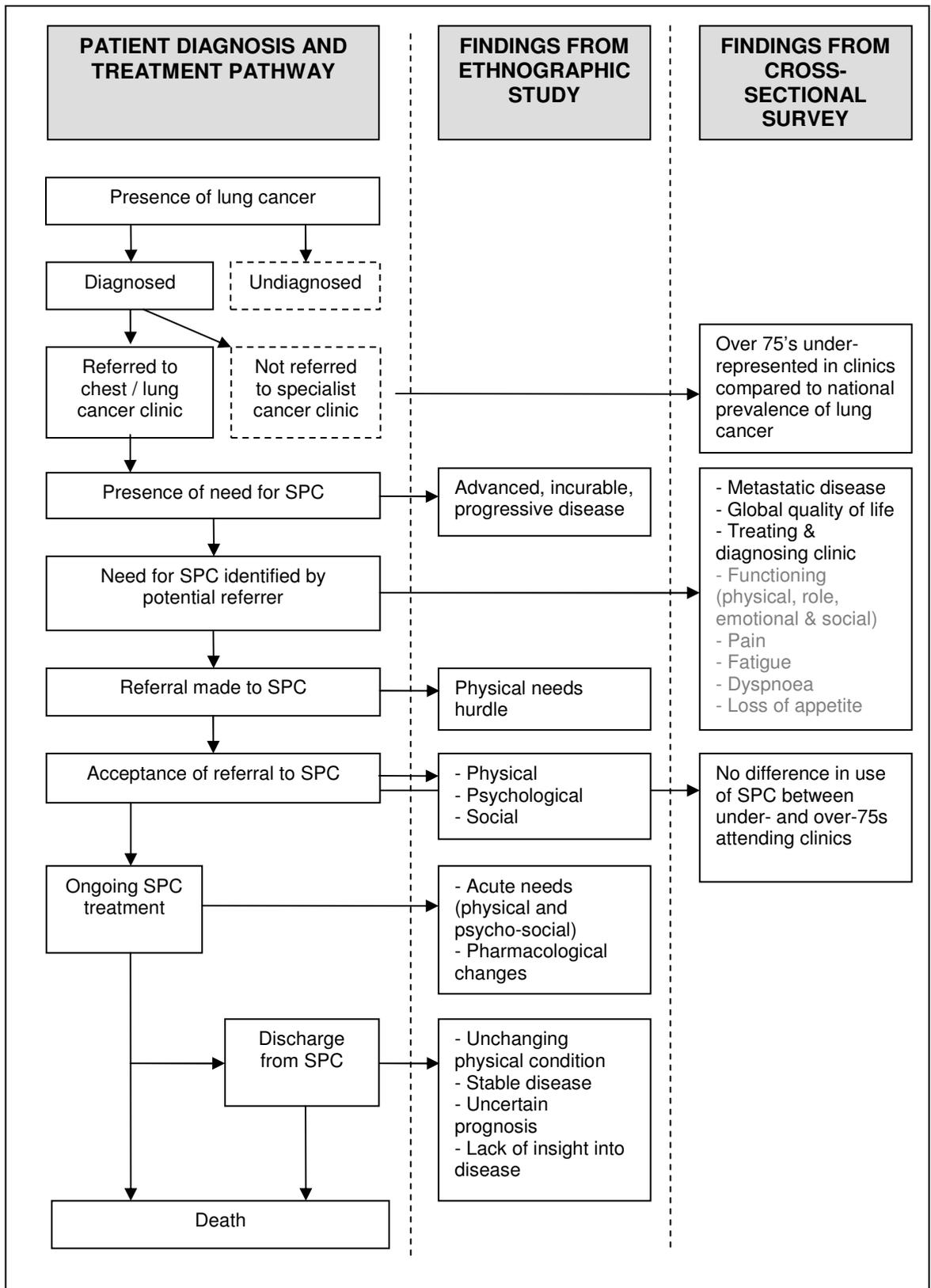


Figure 8.2 Determinants of use of SPC – findings from qualitative and quantitative phases

Once a referral is made to a SPC service, the patient and their carers are assessed against a holistic concept of need, covering in particular the physical, psychological and social domains of care. Whilst spiritual concerns are documented as influencing the prioritisation of patients for care, in reality these are rarely fully assessed.

For patients receiving SPC, an implicit idea of ongoing need is based on a model of acute reactive care. This focuses in particular on the physical, but may be shifted to concentrate on psycho-social issues where these are especially urgent. This model of need reflects the biomedical paradigm of care of a predominantly clinical and nursing staff, and the resource limitations within which they work.

Whilst age is not related to use of SPC, and my ethnographic work suggested no explicit age discrimination, I do, however, have some concerns about the influence of age in access to and provision of care.

Firstly, over-75s were under-represented in participating cancer clinics. Potential reasons for this were discussed in full in Chapter 7, including the impact of the inclusion of a cancer centre with a younger age profile, and the possibility of alternative care pathways as a result of patient age. In the absence of further research examining the locations of care and treatment received for all lung cancer patients in relation to age, my concerns are speculative. However, there remains the possibility that older lung cancer patients may be less likely to receive specialist oncology care, in contradiction of NICE guidance which state access should be provided regardless of age.²³⁷

Secondly, my qualitative findings suggest that the nature of SPC may on occasion differ as a result of patient age, with older patients receiving lower quality care. I observed that older patients may be more likely to wait for an inpatient SPC bed, or were less likely to be offered a bed in a private room rather than on a ward. Younger patients may be regarded as 'special' or particularly tragic and thus deserving of different levels of care. However, I was not able to measure intensity of care (in terms of numbers of contacts with SPC staff and treatments received), or explore this matter more deeply with SPC staff, so this remains a speculative point.

8.2 Limitations of the study

A clear theoretical and methodological base underpins this study. Research into concepts of social justice, equity, need, access and use during the process of study design meant that I undertook data collection and analysis with a strong idea of the approaches I wished to draw upon. This sets the study apart from previous research in the field, which has either failed to define need for SPC, or has used a limited definition such as a diagnosis of cancer or the presence of pain. However, this approach also had its challenges, which I outline below.

My attempt to operationalise the concept of capacity to benefit through ethnographic work in conjunction with a systematic review of HRQL instruments may be questioned on a number of levels. The findings from my ethnographic study and the models of need I derived from these may not be replicated by other researchers (due to differences in individual knowledge, experiences and approach), or in other settings (due to differences in practices and procedures). Using HRQL as a proxy for SPC need is only one option; alternative formulations may focus on specific key symptoms or indicators of disease severity such as stage of cancer. However, in my view

these more limited approaches do not fit with the holistic aims of SPC. I matched domains of SPC need to existing HRQL instruments to assess content validity. However, due to the requirements of instrument scoring, in my primary analysis I used only global quality of life to approximate need. Thus, although I developed a comprehensive conceptualisation of need, this was not what I was able to examine in practice. However, the conduct of further exploratory analyses on specific dimensions of need and their association with SPC use goes some way to alleviating this. In spite of these concerns, the use of a HRQL instrument as a proxy for need is a step forward compared to previous work in this field.

My primary outcome of interest was use of, rather than access to SPC. Whilst conceptually access is the more important of the two (reflecting the political commitment to equity of access, rather than simply use, of health care ⁴⁵³), in practice this is difficult to measure. Understanding whether patients have the opportunity to use SPC, rather than whether they have used SPC, requires an understanding of the true availability of these services, a measure which in practice is almost impossible to ascertain.

I measured use of SPC as being on the caseload of a SPC provider. This provided a simple dichotomous outcome of 'SPC' or 'no SPC'. I did not attempt to measure intensity of care, in relation to the nature and level of contact patients had received from the service up until their participation in the study. Such information may be able to give useful insights into how the care provided varied on the basis of patient characteristics such as age, and would have provided a more robust and detailed measure with which to investigate the presence or absence of equity. However, obtaining and using such information was outside the resources of this study. In addition, the sample size was not sufficiently powered to examine vertical equity.

The use of mixed methods broadened the research questions I addressed, and deepened the inferences I drew. Using techniques drawn from qualitative and quantitative traditions meant I was able to weave together ideas about need with the measurement of need. The pragmatic grounding of the study enabled me to use whichever methods would best answer the question at hand, and freely draw upon all techniques when necessary (such as the quantification of some qualitative data) to develop my analysis. This was essential in developing a comprehensive picture of the organisation of SPC for lung cancer patients within the study area.

The study is limited by its inclusion of only a proportion of the care providers within only one cancer network. The addition of all the cancer units within the network would have enabled me to develop a more complete picture of care. Further, the participating network is a mainly urban area with historically strong SPC provision and major teaching hospitals providing access to the latest lung cancer treatments. The study would have been strengthened by including a contrasting cancer network with different organisation and provision of SPC and lung cancer care. For example, patterns of access to and use of SPC may differ considerably in rural areas in England. Including additional participants would, of course, require additional research capacity, which study funding did not allow.

The study could have been further enriched by the inclusion of the planned third phase of work, interviews with lung cancer patients and referring health care professionals to examine demand and supply side factors influencing referral to and uptake of SPC. These alternative perspectives on need for SPC and the decision-making process around referral to or acceptance of care are an important aspect of explaining variations in use. Their undertaking would bring greater understanding of the issues at hand,

particularly the influence of age on patient pathways. For example, interviews across a diverse age range would have facilitated the exploration of patient attitudes towards the natural process of ageing, expectations of care in relation to age, and attitudes towards death, dying and specialist palliative care. Differences in attitudes may have an important impact on patient-defined need for care; interviews with referring professionals would have introduced further ideas about the relationship between age and need for care at the end of life. Patient interviews would also enable exploration of the particular experiences of lung cancer patients in their receipt of and desire for care, an important and currently under-researched topic.

A number of the issues summarised above relate to the scale of the study. A larger funding application, building on the work presented here, would support a multi-centre cohort study to address issues of vertical and horizontal equity and patient experience across all settings. Yet the underlying conceptual difficulties are relevant to all sizes of study; how best to define, operationalise and measure need remains a challenge within this field. The work presented here represents a considerable step forward in addressing this issue, but more needs to be done at the theoretical level to inform the development of robust methodology to investigate inequities.

I turn now to consider the inferences that may be drawn from my study findings. Drawing upon the theoretical underpinning of the work, I relate my results to dominant theories of need for health care and concepts of social justice.

8.3 Need for specialist palliative care

Need for health care may be assessed either at the level of the population or the individual [Figure 8.3]. Needs assessments are conducted for the

purposes of distributing health care resources at a macro level (in the form of health care planning), or at a micro level (in clinical decision making). The aim of needs assessments may be to ensure equity within a community, or prioritise those most in need, or (as we have seen with current Government policy ⁶), some mixture of the two. Assessments of need may use quantitative, qualitative or mixed approaches to achieve their goal. Whilst population-level assessments tend to draw upon epidemiological data, clinicians may use information from multiple sources to inform their decision on the nature of care to offer. Within this study, I was concerned with clinical decision-making and with identifying need at an individual level. However, I drew upon a primarily macro-level concept of need (that of capacity to benefit) to inform my approach.

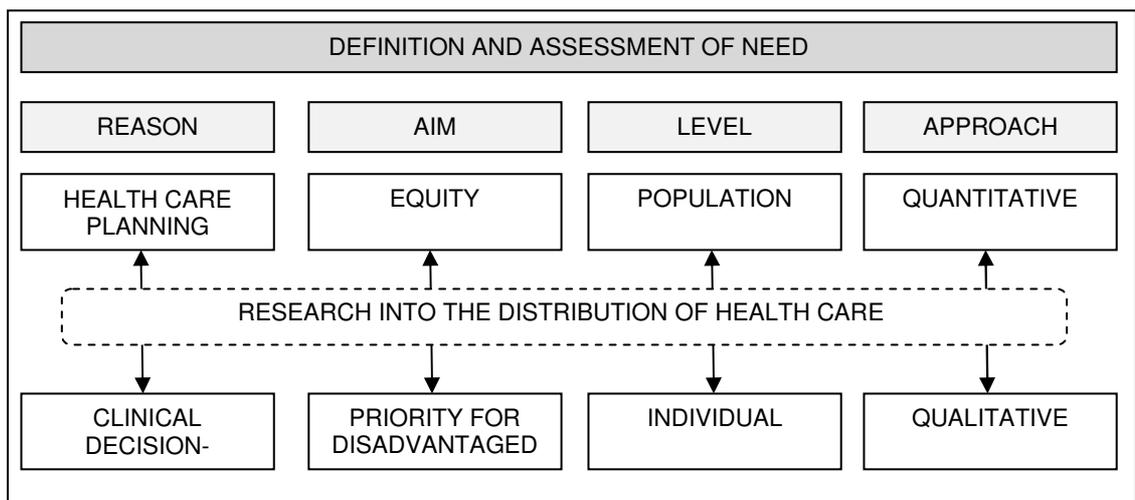


Figure 8.3 The definition and assessment of need in health care planning and delivery

Drawing on the idea of capacity to benefit, I derived two models of need for SPC. The first, 'aspirational' model is holistic. It suggests a clear link between capacity to benefit and physical, psychological, social and spiritual domains of both the patient and their family. The second, 'actual' model is more restricted. It suggests the capacity to benefit is more closely aligned to physical aspects of care for the patient.

These alternative formulations highlight the fluid nature of need, its 'infinitely contestable' nature.⁷⁴ Sociological studies on clinical decision making have provided clear evidence that need for care is shaped through a discourse that incorporates implicit categorisations of patients and a wide range of social factors.^{91;92;323} As I observed, prioritisation of patients was a subtle and fluid process; whilst a primarily biomedical model of need formed the backbone of a patient assessment, this was woven into an analysis of the available resources and an acknowledgement of characteristics including age. This complex reality must, however, be reduced to a measurable phenomenon if we are to research the equitable provision of care using quantitative methods. The move from qualitative to quantitative and from nuanced to clearly defined is challenging; some of the limitations have already been outlined above.

I believe that the aspirational model of SPC need is a useful one. Firstly, it provides a strong conceptual framework for the design and implementation of SPC services. Secondly, it is the model SPC staff use to assess patients, even if their subsequent delivery of care is not as broad in scope. However, the evidence of effectiveness to support this model – particularly in the social and spiritual domains – is limited at present.²²³ This is a weakness when concepts of need for health care stress the importance of that health care being effective.²⁴ Thus, the evidence base to support this model must be expanded. If there is evidence of effectiveness across all dimensions, more resources may be directed towards implementing comprehensive SPC services.⁴⁹⁹

In the light of current resource limitations, it may appear more sensible to use the primarily physical, 'actual' model of SPC for policy and planning purposes. A focus on the relief of physical suffering requires fewer resources

than a holistic approach to care. Further, as the proportion of older people in our population expands and demand for end-of-life care subsequently increases, resources may become even more limited.

However, there is a theoretical justification for SPC services to continue to strive to implement the 'aspirational' model of care, and improve the nature of the care provided to all their patients. Jennifer Prah Ruger, amongst others, has argued for the importance of the concept of 'shortfall' in assessing the equity and quality of health care.⁵⁰⁰ I discuss this in more detail below, but the idea of assessing the gap between the care which is actually delivered and the highest attainable standard of care is relevant here. The aspirational model of SPC may be attainable with sufficient resources and an experienced multi-disciplinary team. As I have discussed in this thesis, patients *are* initially assessed against multiple domains of need, but the decision making process and the provision of ongoing care tends to be weighted toward the physical. Within the concept of 'shortfall equality', inequality results for anyone who receives less than the highest standard of care. The retention of an aspirational model of need thus serves to provide a gold standard against which to measure performance. This is a demanding measure to meet, but it lends support to continuing to set out what a sufficiently resourced service should achieve.

I would argue that the continued existence of an 'aspirational' model of need does not imply that the 'actual' model of need is necessarily problematic at present. I did not undertake interviews with patients as planned, so I am not able to conclude whether a primary focus on physical needs is or is not acceptable from their perspective. Research suggests that satisfaction with SPC, particularly within hospices, is high, although there are concerns about the methodological rigour of studies conducted to date.⁵⁰¹ However, it

remains likely that, in spite of the potentially reduced nature of care many patients receive against the 'gold standard' aspiration, benefit (in terms both of patient satisfaction and symptom relief) is still delivered. SPC is a relatively young movement within medicine and nursing, and continues to strive to improve its evidence base and models of care delivery. Within the UK, shifts in funding and Government policy have contributed to difficulties in fully achieving goals of care; this may change in the future.⁵⁰² Whilst services and evidence continue to develop and expand, the effective relief of physical symptoms for those in the last months of life remains an essential part of our health care system.

The existence of both 'aspirational' and 'actual' models of need within one specialty, and the requirement to understand these both qualitatively and quantitatively, requires clarity about the purpose, level and nature of any needs assessment undertaken. Capacity to benefit is an instrumental theory of need, based on the idea that health care is required to achieve a particular end state, such as improved quality of life. However, in practice such instrumental concepts may be subsumed within normative assessments of need based simply on the belief of a SPC provider that care should be given to a particular patient, without reference to the goal of that care. Yet, I have demonstrated that capacity to benefit still has utility in guiding examinations of clinical decision-making. The greatest challenge in much research into need will be moving between the micro and the macro, between qualitative and quantitative assessments, whilst maintaining clarity about the phenomenon at hand. Below, I develop further the role of need within equity research and its relevance to theories of social justice.

8.4 Aspects of equity and priority

The current Government's drive for equal access to SPC, regardless of patient characteristics such as age, stems from their concern with social justice. In the background to this thesis, I outlined alternative theories of social justice, aligned to egalitarianism (opportunities approaches and the capabilities approach), prioritarianism, and sufficientism. Broadly, these are concerned either with the achievement of equality in access to health care; targeting access to health care for the worst off to raise them from the lowest level of health; or with ensuring adequate health care for everyone.

To date, egalitarian ideals have dominated health policy and research, on the basis that everyone should have equal access to effective health care to achieve their full health potential.⁵⁰³ However, there is evidence that within the context of limited resources the focus moves to prioritisation of the worst off at both the macro (population) and micro (individual) level.³²² Further, in circumstances of severely limited resources, ensuring that everyone receives a basic minimum standard of care may be the most pressing concern.⁵⁰⁴ Strict adherence to one theoretical ideal is therefore unlikely to happen in practice, as current Government concerns with both reducing inequities and improving the position of the worst off shows.⁵⁰⁵

I focus here on egalitarian theory, as my investigation was based on the policy goal of ensuring equal access to SPC on the basis of need. Whilst both opportunity and capability-based accounts support the goal of equal access to care, the reasons behind their support and the detailed formulation of what this entails differ. Opportunities-based theories, derived from the work of Rawls, justify the fair provision of health care on the basis that it secures opportunities for individuals within society. As loss of normal human functioning may be addressed by the provision of care, Rawlsian approaches associate an equal right to health care with the broader requirement to

promote equal opportunity within society.³⁷ A capabilities-based defence of equal access to health care takes a broader approach, arguing the goal is not removing barriers to opportunity, but a deeper aim of ensuring the social conditions in which all individuals have the capability to be healthy.⁴⁸ It is the capabilities-based approach which I feel has particular relevance to the findings presented here.

The capabilities-based approach provides a framework through which assessments of wellbeing, including investigations into inequalities, may be conducted. However, a capability theory of justice has not yet been fully developed within political philosophy; further, the capability approach lends itself to the development of more than one theory of justice.⁵⁰⁶ Regardless of this, attempts have been made to draw upon the capability approach to assess inequalities. As outlined in Chapter 2, Wolff and de-Shalit have provided one formulation through which to assess injustice, suggesting that society should focus on 'genuine opportunities for secure functioning', which requires, in the context of limited resources, an initial prioritisation of the worst-off.⁶² They suggest how this might relate to inequalities in health care; whilst decisions to offer care will be based on clinical need, these will be taken within a broader context aiming for the most efficient distribution of resources to improve the position of the most disadvantaged. Whilst this theory was specifically formulated to have direct policy relevance and provides a useful framework to guide strategy, it is another capabilities account, derived specifically to relate to health care, I find most useful here.

The 'health capability approach' recently developed by Jennifer Prah Ruger incorporates health care quality, health agency, and health norms within assessments of health care inequalities [Figure 8.4].^{46;48} In formulating this theory, Ruger draws both on Sen's capability approach and on Aristotle's

political theory.⁴⁸ Its broad approach to inequalities in part reflects Margaret Whitehead's influential formulation of equity, which stressed the importance of considering access, use *and* quality in investigating variations in health care.²³ Below, I consider how the major concerns of the health capability account (the concept of shortfall equity and the principles of horizontal and vertical equity) and the three domains through which to assess inequalities under this account (health care quality, health agency and health norms) relate to the findings of this study.

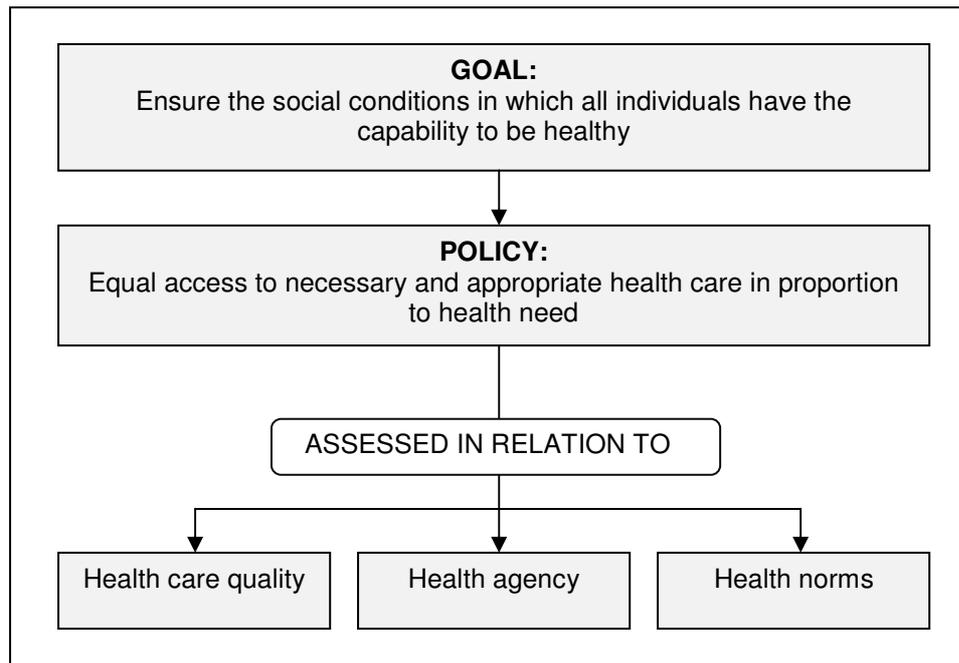


Figure 8.4 Ruger's Health Capability Account

Firstly, Ruger's account does not require equal outcomes amongst people in terms of achieving equal health or receiving equal amounts of healthcare. Instead, it concentrates on evaluating disparities in terms of 'shortfall equality'. This concept considers the deficit in achievement from an individual's potential for health, or from a health care services' potential to deliver.^{47;48;507} Thus, equity should be assessed by considering how far experiences of SPC fall short of the agreed standard of care all patients are expected to receive. Systematic differences between groups, such as older and younger patients, in gaps between expected and received care would suggest inequities. This pursuit of a 'gold standards' of care is challenging, although Ruger urges society to take this challenge on.⁴⁸

'Shortfall equality' is a useful approach to considering the role of the 'aspirational' model of SPC, and the 'actual' model of SPC I derived. The aspirational model serves to underpin efforts both to improve care, and to

improve the evidence base for care. The actual model focuses attention on current experiences of care and whether these are agreed to be deficient or not. Under the concept of shortfall equality, *all* patients receiving a more restricted model of SPC may be disadvantaged, as there is a gap between the care they receive and the 'gold standard' of care.

A second dimension of the health capability account is that the allocation of resources should follow the idea of proportional distribution derived from the Aristotelian principles of horizontal and vertical equity (like treatment for like, and unlike treatment for unlike). Thus, individuals with greater needs should receive more health care resources to restore their health functioning as far as possible, as long as other individuals with similar needs receive the same level of care.⁴⁸ Ruger suggests that health care should be offered only if it is necessary and appropriate, aspects which should be assessed by patients and their clinicians. This formulation of equity highlights the importance both of meeting the needs of all, whilst acknowledging that some needs are greater than others.

The prioritisation of patients within SPC, and the subsequent devotion of greater resources to them, would thus be justified on the basis that 'individuals merit the resources they need to reach a medically determined level of health functioning'.⁴⁸ The complex discussions I observed at inpatient admissions meetings as to which patients should be admitted to a limited number of beds represent the efforts by SPC staff to understand and prioritise levels of need. For example, home care patients referred for inpatient care were prioritised over hospital patients, who were deemed to be in a 'safe place' and thus less requiring of care. Principles of vertical and horizontal equity are further reflected by my finding that the 22 survey

participants referred to SPC on the day of diagnosis (23% of all those receiving SPC) all had metastatic disease by this time.

What Ruger's theory cannot do is provide insight into whether the formulation of need for SPC on which access is based is acceptable. She suggests that decisions about which health care services to provide, and to what level, should be taken using a decision-making framework integrating both clinical and economic considerations, and based on both procedural and substantive principles.⁴⁶ Thus, policy-makers, the public, patients and clinicians may agree that the provision of the 'actual' (predominantly physical) model of SPC may be the best approach within current resource limitations. As such, the current model of care identified here would be unproblematic. However, it is also likely that the health capability account would support the retention of the 'aspirational' view of need as an ideal to work towards. As noted above, interviews with patients and referrers to SPC services would here be useful to start to explore expectations of and satisfaction with models of care.

The health capability account suggests three dimensions through which health care inequalities should be assessed. Firstly, it is concerned with the achievement of high quality care for all. Ruger argues that differences in health care quality are 'morally troubling and unjust'.⁴⁸ Such differences undermine individual's capability for health functioning. Thus, people with the same health condition should enjoy the same access to care. My observations that older people may wait longer for an inpatient hospice bed, or receive different levels of care once admitted, would thus highlight a breach of standards of equal access. A full examination of equity drawing upon the capability approach would demand a consideration not just of

outcomes – whether a patient received SPC or not – but also what happened to each patient under the care of a SPC team.

The second dimension, health agency, is concerned with the ability individuals have to use the high quality health care available to them to attain the highest possible health functioning. Health agency:

...includes more than health knowledge, but effective decisional balance with respect to health, self-management and self-regulation skills, and ability to command control of personal and professional situations to pursue health, among other important qualities. ⁴⁸

Individuals may vary in the degree of health agency they enjoy, and the health capability account places a responsibility on society to nurture a minimal level of health agency for all. Older cancer patients may, for example, be less likely to recognise important symptoms, to negotiate access to health care, to communicate with health care providers, and to be able to self-care. ^{160;508} Reduced levels of health agency amongst older patients may thus be an important dimension of equitable access to SPC, including the level of service received once patients are on the caseload of a provider. However, without interviews with patients to explore this phenomenon, no further understanding of its impact on SPC access may be derived.

The final dimension of the health capability account is a concern with health norms. Health norms are beliefs about health, ill-health and health care that influence choice at the individual and community level. ⁴⁸ Societal norms may result in social exclusion and disadvantage. Here, an opportunities-based account would focus on changing the situation of a disadvantaged individual (for example, an elderly cancer patient) through the provision of

resources (for example, health care). A capabilities-based account, by contrast, would provide appropriate health care whilst also striving to change norm-based inequalities and improving opportunities for health agency. Thus, if social norms suggest older cancer patients do not have equal moral worth and are as a result excluded from aspects of care, the pursuit of equal access to health care must involve tackling deep-rooted attitudes across wider society.

I observed that SPC attitudes towards older and younger patients may vary. Deaths of younger patients were commented on as particularly tragic or shocking, echoing previous findings that within SPC deaths occurring at a young age were seen as 'bad' deaths.⁵⁰⁹ Concerns were expressed about the nature of care provided for older patients within SPC, and ensuring providers were not drawn into aspects of care deemed unsuitable for them; as one doctor cautioned '*she is an elderly lady like a lot of elderly ladies out there*'. One clinician directly acknowledged that the service was likely to make more of an effort for younger patients. These suggest the existence of norms within SPC, reflecting those of wider society, in which older patients are perceived as less deserving of care. Whilst the policy and legal context may strongly discourage age discrimination, changing implicit values and attitudes is more challenging.⁸

The under-specification of capability theory means that it should be partnered with additional or alternative theories in seeking to examine phenomena of interest.⁵¹⁰ Ruger does not specify how need for health care may be conceptualised, operationalised and measured, simply stating that within her approach equal access to care is based on need for necessary and appropriate health care. The concept of capacity to benefit from care is one that is used widely within the health economics and public health literature,

and is useful here in providing an approach to determining the dimensions of import. Capacity to benefit may include multiple dimensions of care, as within SPC.²⁶ However, the requirement that care should additionally be effective highlights the need for an expansion of the SPC evidence base to enable the field to meet its aspirations.

The capability approach has been adopted within a pragmatist perspective by Zimmermann.²⁹² As with pragmatism, Sen's formulation of the capability approach rejects utilitarianism's narrow conception of action as being motivated by the achievement of desires. Instead, both emphasise the importance of ability and freedom to achieve, rather than achievement itself. Further, Sen's commitment to the role of human agency (including motivations, beliefs and emotions) and the influence of environmental and economic circumstances on that agency echoes the pragmatist conception of 'situated action', the interaction between agency and the environment.²⁹² Finally, the link made by Sen between knowledge and action is paralleled in the pragmatist approach to inquiry, seeking both to develop knowledge and to drive corresponding changes in political values and commitments.

The ethical dimension to both pragmatism and the capability approach provide strong support for research into inequalities which is driven by a belief in the moral importance of understanding and taking action against disadvantage. Additionally, considerations of individual agency and context highlight the need to incorporate a temporal dimension to such research. Agency, opportunities, capabilities and environmental factors may vary throughout the course of an individual's life, or throughout a disease trajectory, as well as a result of characteristics such as age.²⁹² Thus, factors which promote or impede access to care may differ between one time point and another, and between one individual and another. This supports the use,

where possible, of methods which enable investigation into the whole patient journey. Finally, a pragmatic and capability-based understanding of agency and context supports the examination of the complex processes generated through the interplay between macro, meso and micro elements; of how inequalities may arise through the interaction of population-level policy with individual-level decision making. Mixed methods approaches provide a useful approach to investigating these multiple dimensions of care.

In examining equity of health care access, I believe that Ruger's framework of health agency, healthcare quality and health norms is an important development in building a comprehensive understanding of inequities. The use of both qualitative and quantitative methods enables investigation of each of these dimensions to achieve a holistic understanding of the processes and outcomes of care. Finally, a capabilities approach underpinned by a pragmatic philosophy enables researchers into inequalities to acknowledge the ethical and moral dimensions of their work.

I would therefore conclude that, whilst I did not find disparities in use of SPC between older and younger patients, this is not sufficient to suggest inequities are not present. Regardless of age, patients with equal needs should receive the same level and quality of SPC, and should additionally be supported in recognising their needs. As already acknowledged, in this study I was not able to address every dimension of the health capability account required to comprehensively identify disadvantage. Below, I outline how future research may continue to add to our understanding of equitable SPC.

8.5 Recommendations for research and policy

In this study I considered the experiences of patients within the specialist cancer care system. This setting is not representative of the experiences of all patients with a diagnosis of lung cancer. As my findings suggest, the age distribution within these clinics is unlikely to reflect the age distribution of lung cancer incidence within England as a whole. The question remains, therefore, whether access to SPC is equitable by age for *all* lung cancer patients regardless of treatment setting. This would require study of patient pathways to SPC (or not) across all potential locations of care. Ideally, recruitment would start within the primary care setting. More realistically, studies would encompass all potential locations of secondary care for lung cancer patients, including care of the elderly, general medicine, oncology, and A&E. This would enable a comprehensive understanding of the treatment received by all patients, and how this varied by age.

Originally I set out with the aim of conducting a cohort study to investigate not only access to SPC, but also the nature and level of SPC received. This was not achievable with the resources available, but is an important next step if we are to obtain the best possible evidence on use of SPC, and particularly the presence or absence of vertical equity. As already outlined above, the ideal would be to follow patients from GP referral for investigation of lung cancer (or presentation within A&E) to death, with an additional assessment following death to determine the bereavement services family and friends receive. This would be resource intensive, but would form the most robust approach to examining both the full patient pathway and the nature of SPC received.

Data on the precise amount and type of SPC received – telephone consultations, home visits, clinic appointments, inpatient stays – would

enable a detailed examination of the proportionality of care. Do patients with similar needs (in terms of stage of disease or type and 'troublesomeness' of symptoms) receive similar levels of care? Are there disparities by age? This would provide greater understanding of whether equal quality of care was offered.

The aspirational model of need I derived highlights the importance of understanding whether SPC approaches to the provision of psychological, social and spiritual support are effective. Building this evidence base would have implications for both policy and practice. Firstly, if there were positive evidence for the impact of SPC on these less tangible dimensions, providers would be able to shape their services around the most effective model of care. Researchers would better understand whether we are to assess equity in care delivery against a reduced or more holistic model of need. Finally, policy makers would be able to consider whether SPC should receive more resources to support their development of the holistic 'physical, psychological, social and spiritual' model of care.

The tension between quantitative and qualitative accounts of need for health care, and SPC in particular, remains a challenge. Further exploration of the construction of patient need within clinical discourse would enable greater understanding of the processes by which use of health care is determined. Within SPC, attempts to develop a suitable measure of need for care are ongoing (see for example ⁵¹¹). Whilst this study used HRQL as an indicator of need, alternative formulations could incorporate known dimensions of the decision-making process to provide a more refined measure.

Finally, the capabilities approach has interesting implications for assessments of equity. Methodological approaches to the fair provision of

care have to date focused primarily on use of health care alone. Incorporating assessments of quality, agency and norms into research studies would require a wider scope to enquiries, including an understanding of how our culture contributes to health care provision, access and use. Mixed methods would be particularly suited to this task, facilitating the combination of quantitative measures of quality and access with qualitative explorations of social norms and health agency.

It is difficult to make clear policy recommendations when much further research is required. If, for example, the holistic measure of need for SPC is demonstrated to have a robust evidence base, this will have implications for the resources required to enable patients at the end of life to receive the highest quality care, including psycho-social support. Additionally, more information about the care pathways of older lung cancer patients is needed before further action can be taken at a policy level to address any potential inequities of care.

The health capability account, incorporating health quality, agency and norms, highlights the importance of formulating health care policy across all Government departments. In particular, changing potentially negative health norms about ageing requires action across the whole of society. Whilst the Equality Bill introduced in 2009 highlights the need to tackle deep-rooted attitudinal issues in all arenas, changing individual behaviour and organisational culture remains a challenge for policy makers keen to achieve equity.⁹

Summary

In this thesis I have presented research drawing on theory and evidence from a range of sources, including philosophy, economics, and public health. The goal throughout has been to contribute to our understanding of the fairness of health care; to do so, I focused on the experiences of lung cancer patients, and the specialty of SPC. As I have outlined previously, fairness is a contested concept. So are need, use, quality of care, old age and other issues central to this work. Throughout my research, I have endeavoured to learn about, consider and critique the various approaches to these concepts, eventually drawing upon those that sat best with my research outlook and the subject at hand. Thus, I have utilised a pragmatic, mixed methods approach to guide the design and conduct of my studies. I have taken an instrumental concept of capacity to benefit to guide an operationalisation of need for SPC. I have chosen an existing to HRQL instrument to measure this need. Finally, I have drawn on a capability account of health to explain my findings of use and quality of care, and to highlight the need for more comprehensive examinations of pathways to care to inform policy.

Previous research in this field has commonly concluded that older people are less likely to access SPC. However, this research has also neglected to conceptualise, operationalise and measure need for SPC. I did not find evidence of inequity of SPC in my study sample, but I did uncover some evidence that older people may be disadvantaged in their receipt of appropriate cancer and end-of-life care. This project demonstrates the feasibility of incorporating a measure of need into considerations of use, and of gathering data directly from patients and carers rather than relying on retrospective records or reports. It also highlights the strength of mixed methods in examining the multiple dimensions of health care equity necessary to develop a full understanding of variations in use and quality of

care. I hope that it represents one small additional step towards achieving the goal shared by so many; the reduction of injustice and disadvantage in our society.

*What we call the beginning is often the end
And to make an end is to make a beginning
The end is where we start from*

TS Eliot. Four Quartets 'Little Gidding' ⁵¹²

Appendices

- Appendix I: Lung cancer diagnosis and treatment
- Appendix II: Documentation for ethnography of specialist palliative care providers
- Appendix III: Critical appraisal of HRQL instruments
- Appendix IV: Pilot study of equity of use of specialist palliative care
- Appendix V: Documentation for cross-sectional survey of lung cancer patients and carers
- Appendix VI: Journal papers arising from this work (published and submitted)

Appendix I

Lung cancer diagnosis and treatment

This appendix sets out full details of the current treatment regimes available to lung cancer patients within the UK, to provide context to the findings of the survey on SPC use by lung cancer patients.

Staging and treatment

Treatment options for lung cancer are determined by the stage of disease, along with performance status and the presence of relevant comorbidities.

Disease stage is a clear indicator of expected prognosis.⁵¹³

Non-small cell lung cancer (NSCLC) is staged using the TNM system:

- T to indicate the size and location of the primary tumour
- N to indicate spread to regional lymph nodes
- M for distant metastasis

These are then classified into stage groupings ranging in severity from I to IV [Tables 1 and 2]. Whilst small-cell lung cancer (SCLC) can in theory also be classified using the TNM system, in practice it is grouped into two stages, limited or extensive disease. Limited disease is defined as being where all detectable tumour can be encompassed within a radiotherapy port.

Extensive disease includes patients with metastatic lesions in the other lung, and those with distant metastatic involvement.

Table 1. The TNM staging system for NSCLC ²³⁷	
Primary tumour (T)	
TX	Primary tumour cannot be assessed, or tumour proven by presence of malignant cells in sputum of bronchial washings but not visualized by imaging or bronchoscopy.
T0	No evidence of primary tumour.
TIS	Carcinoma in situ.
T1	Tumour < 3cm in greatest dimension, surrounded by lung or visceral pleura, without bronchoscopic evidence of invasion more proximal than the lobar bronchus (that is, not in the main bronchus)
T2	Tumour with any of the following features of size or extent: - > 3cm in greatest dimension - involves main bronchus - > 2cm distal to the carina - invades the visceral pleura Associated with atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung
T3	Tumour of any size that directly invades any of the following: diaphragm, mediastinal pleura, parietal pericardium; or tumour in the main bronchus < 2cm distal to the carina, but without involvement of the carina; or associated atelectasis or obstructive pneumonitis of the entire lung.
T4	Tumour of any size that invades any of the following: mediastinum, heart, great vessels, trachea, oesophagus, vertebral body, carina, or tumour with malignant pleural effusion or pericardial effusion or with satellite tumour nodules within the ipsilateral primary-tumour lobe of the lung.
Regional lymph nodes (N)	
NX	Regional lymph nodes cannot be assessed.
N0	No regional lymph node metastasis.
N1	Metastasis to ipsilateral peribronchial and / or ipsilateral hilar lymph nodes and intrapulmonary nodes involved by direct extension of the primary tumour.
N2	Metastasis to ipsilateral mediastinal and/or sub-carinal lymph nodes.
N3	Metastasis to contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene or supraclavicular lymph nodes.
Distant metastasis (M)	
MX	Presence of distant metastasis cannot be assessed.
M0	No distant metastasis.
M1	Distant metastasis present.

Table 2. NSCLC staging – TNM subsets by stage	
Stage group	TNM subset
Stage 0	Carcinoma <i>in situ</i>
Stage IA	T1 - N0 - M0
Stage IB	T2 - N0 - M0
Stage IIA	T1 - N1 - M0
Stage IIB	T2 - N1 - M0
	T3 - N0 - M0
Stage IIIA	T3 - N1 - M0
	T1 - N2 - M0
	T2 - N2 - M0
	T3 - N2 - M0
Stage IIIB	T4 - N0 - M0
	T4 - N1 - M0
	T4 - N2 - M0
	T1 - N3 - M0
	T2 - N3 - M0
	T3 - N3 - M0
	T4 - N3 - M0
Stage IV	Any T Any N M1

There are limited data on the proportion of patients at each stage of the disease at presentation. One UK study of referrals to a cancer unit reported that, of those patients whose disease was staged, 59% of SCLC patients had extensive disease, and 35% of NSCLC had Stage IV disease.⁵¹⁴ However, the high proportion of missing data in the more seriously ill patients in this study means that the actual proportion of patients with advanced disease is likely to be higher.

NICE guidelines on the diagnosis and treatment of lung cancer set out recommended treatment approaches for patients.²³⁷ These are dependent on the stage of disease and characteristics of each individual patient, and are summarised for NSCLC in Table 3. For SCLC, patients are routinely offered chemotherapy, with radiotherapy considered for some. All treatment approaches are described in more detail below.

Table 3. Treatment of Non Small Cell Lung Cancer							
	Stage I	Stage II	Stage IIIA	Stage IIIB	Stage IV, WHO 0-1	Stage IV WHO 2	Stage IV WHO >2
Surgery							
Radiotherapy followed by surgery							
Surgery followed by radiotherapy							
Pre-operative chemotherapy and surgery	a	a	a				
Surgery followed by chemotherapy							
Surgery then chemo- and radiotherapy		a	a				
Radical radiotherapy							
Chemotherapy and radical radiotherapy				b			
Chemotherapy						a	
Symptomatic treatment, including palliative radiotherapy							

Key	
	First choice for eligible patients
	Suitable for some patients
	Not recommended
a Except within a clinical trial	
b May be first choice of treatment for patients with good performance status and localised disease that can be safely encompassed in a radical radiotherapy treatment volume	

Surgery

Surgery is the primary curative treatment available to patients with NSCLC, but only if they have early disease (stage I or II, occasionally IIIA) and good performance status. It is rare for surgery to be offered for SCLC, as by the time of diagnosis the disease has usually progressed beyond the stage where it is amenable to surgical intervention.

Three different surgical approaches are possible, depending on the nature and location of the tumour [Figure 1]. Alongside considerations of the operability of the disease, guidelines set out clear recommendations on

assessing the suitability of patients for surgery.⁵¹⁵ These highlight four areas for assessment: age, pulmonary function, cardiovascular fitness, and nutrition and performance status. The guidelines state that all patients should have equal access to care, regardless of their age. However, whilst it is concluded that limited surgery for both stage I and II disease is effective for patients aged between 70 and 79, for those aged over 80 surgery is only recommended in the context of stage I disease. More extensive surgery in the form of pneumonectomy is considered to be associated with higher mortality in the elderly, and therefore guidelines state that the age of the patient must be taken into account before performing this procedure. Finally, the guidelines draw attention to the importance of comorbidity in determining the likely success of surgery, and the relationship between increasing age and increasing comorbidity.

UK figures show that only around 10% of lung cancer patients undergo surgical resection, although recently higher figures of 17% have been suggested.^{516;517}

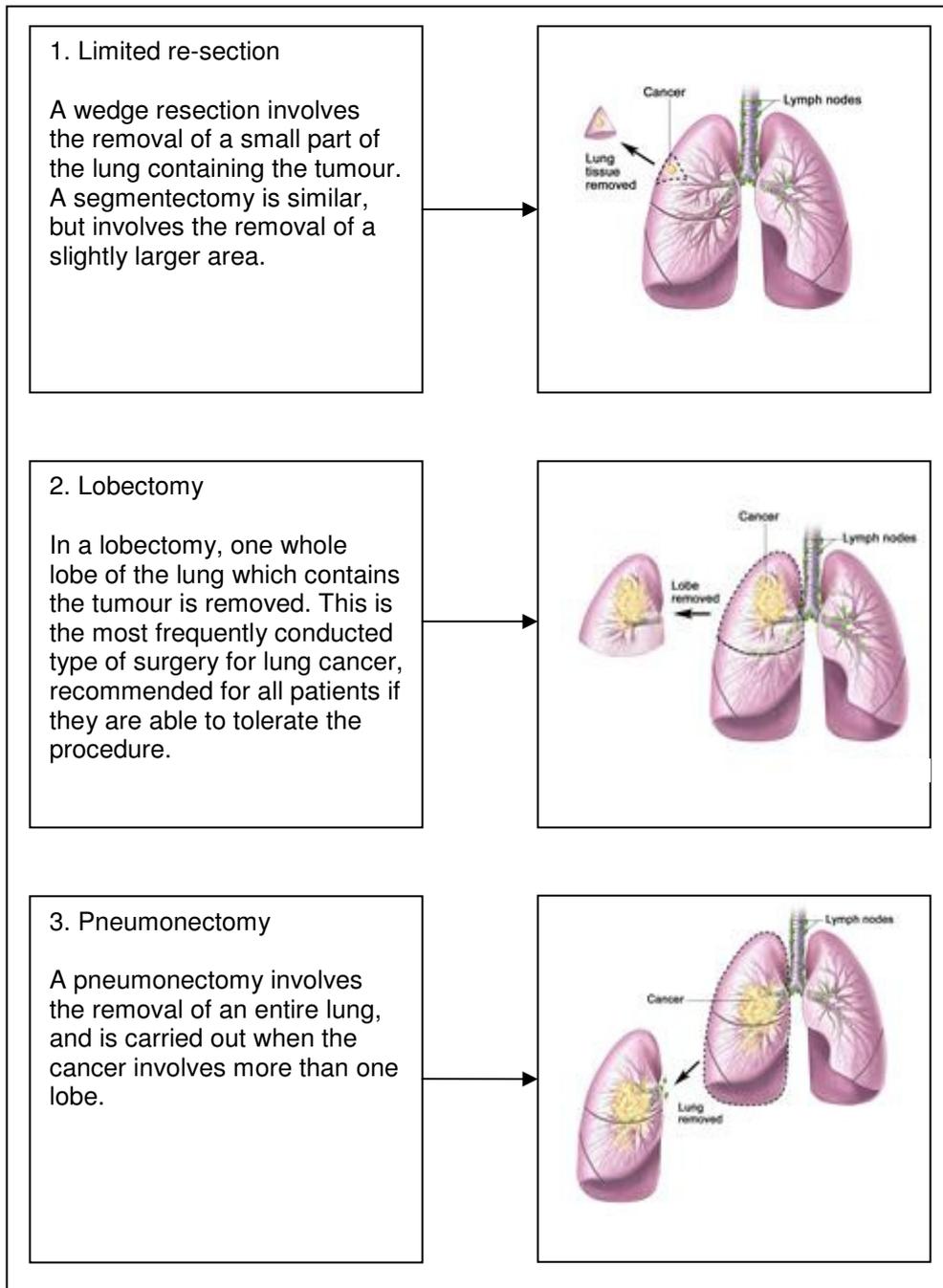


Figure 1. Types of surgery for lung cancer

Radical radiotherapy

Radical radiotherapy is radiotherapy given with the intention of cure or long-term disease control.²³⁷ It may be given in isolation, or in combination with chemotherapy. In stage I and II NSCLC, radical radiotherapy may be offered to those patients who are deemed to be unfit for surgery (due to

comorbidity, for example), or who decline surgery. Individuals with Stage III disease and a good performance status, whose disease is encompassable within a radiotherapy treatment volume, may also be offered radical radiotherapy. Evidence on the effect of age on survival following radical radiotherapy is currently conflicting; some studies have reported better survival in younger patients (defined as 80 or 70 and below, according to the study), whilst others have found no effect.²⁵⁶ Older age is not, therefore, currently regarded as a contraindication to receiving radical radiotherapy.

Radical radiotherapy regimens differ in the total dose of radiotherapy delivered (measured in Grays (Gy)), how this total dose is administered (the number of treatments (fractions) and the amount given in each fraction), and in whether treatments are given on consecutive days, or on Mondays to Fridays only.

The conventional approach to radical radiotherapy in NSCLC offers a total dose of 64-66 Gy in 32-33 fractions over 6½ weeks (Monday to Friday) or 55 Gy in 20 fractions over 4 weeks. However, NICE guidelines recommend an alternative regimen, called CHART, as the treatment of choice for NSCLC patients receiving radical radiotherapy alone. In CHART (Continuous Hyperfractionated Accelerated RadioTherapy) patients receive a total dose of 54 Gy, given in 36 fractions of 1.5 Gy, three times a day for 12 consecutive days – a regimen shown to have significant survival benefits over conventional approaches.⁵¹⁸ However, in spite of the acknowledged effectiveness of CHART, practical difficulties in its administration (requiring radiographers to be available seven days a week) mean that it is currently available in only a few centres in the UK. A subsequent proposed modification of the regimen is CHARTWEL (CHART – weekend-less),

offering a total dose of between 54 and 60Gy three times a day Monday to Friday, ⁵¹⁹ which is currently undergoing further trials.

Palliative radiotherapy

Palliative radiotherapy is offered to patients with both NSCLC and SCLC to offer relief from symptoms including chest pain, breathlessness, cough and haemoptysis. This usually consists of a short course of 10Gy in one fraction, or 16/17Gy in two fractions. A recent Cochrane review found that higher dose regimens of 36Gy in 12 fractions may lead to modest increases in survival, as well as providing effective symptom control, for patients who are fit enough to receive larger doses of radiotherapy. ⁵²⁰

Chemotherapy

Although NSCLC is not as chemosensitive as SCLC, chemotherapy is the recommended treatment for patients with Stage IIIB or IV disease and good performance status. In this context, the aim is not cure but symptom control and small improvements in life expectancy. It may also be used in conjunction with radical radiotherapy in patients with Stage IIIA disease. By contrast, chemotherapy is the treatment of choice for SCLC, which is regarded as a systemic disease usually requiring systemic treatment. In limited stage SCLC, chemotherapy may also be used alongside radiotherapy to improve local disease control.

Chemotherapy is usually given on an outpatient basis as a course of three to six cycles, with three weeks in between each cycle. In advanced NSCLC, patients are recommended to receive a combination of third generation drug (docetaxel, gemcitabine, paclitaxel or vinorelbine) together with a platinum-based drug (carboplatin or cisplatin). SCLC is also normally treated with combination-based therapy with a platinum based drug, such as etoposide

alongside cisplatin. The choice of therapy will depend on the extent of the patient's disease, comorbidity and frailty as well as the availability of such drugs within the treating hospital. For patients who may be unable to tolerate the more toxic platinum-based drugs, single agent therapy may be offered.

Performance status is a key clinical consideration when judging eligibility for chemotherapy. Typically assessed using the Zubod/WHO scale (Table 4), only patients with a performance status of 0 or 1 are usually considered eligible for chemotherapy. Patients with a score of 2 or more who do receive chemotherapy have been found to have lower survival rates, and suffer greater toxicity; treatment is not therefore routinely offered to patients with poor performance status.²³⁷

Table 4. Zubod/WHO Scale of Performance Status	
Score	Definition
0	Asymptomatic
1	Symptomatic, but ambulatory (able to carry out light work)
2	In bed < 50% of day (unable to work but able to live at home with some assistance)
3	In bed >50% of day (unable to care for self)
4	Bedridden

Best supportive care

Best supportive care is the name commonly given to the management of disease-related symptoms in lung cancer patients where cure is not possible.⁵²¹ It may involve the receipt of both chemotherapy and radiotherapy where the aim is symptom control rather than prolongation of life. Patients are monitored and symptoms and other concerns addressed as they develop; it does not necessarily mean a referral to a SPC team has been made.

Appendix II

Documentation for ethnography of specialist palliative care providers

This appendix contains the documentation used in the ethnographic study of SPC providers, exploring their concepts of need for, and factors influencing use of, SPC for cancer patients. This comprises:

- Participant information sheet
- Participant consent form (observation)
- Participant consent form (interview)
- Interview topic guide

Defining need for specialist palliative care

Information sheet for participants

You are being invited to take part in a research study. Before you decide whether to take part 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 me 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.

What is the purpose of the study?

One of the basic principles of healthcare in the UK is that it is provided on the basis of need, and need alone. Research into variations in the use of healthcare services therefore requires information on patients' need for this care, as well as their use of it. This is so we can understand whether differences in patients' use of healthcare are simply due to differences in those patients' need for care, or whether differences in use are due to other factors such as gender or socio-economic status.

This study forms one part of a Medical Research Council (MRC) funded research project looking at variations in the use of specialist palliative care services by lung cancer patients. In order to look carefully at how and why use of specialist palliative care varies in this group, it is important for us to develop an in-depth understanding of how need for this type of care can be defined and measured. However, at present there is little information on how need for specialist palliative care is perceived by providers of such care, and how it can be assessed within the context of a research study. Therefore, the aim of this study is to develop a conceptualization of need for specialist palliative care, and investigate whether any existing quality-of-life instruments can be used to measure this need.

The study involves a comprehensive literature review, observation of meetings of specialist palliative care providers, and one-to-one interviews with specialist palliative care providers.

This study will take place over the course of a year, although the wider programme of work will take place over the next three years.

Why have I been chosen?

You have been chosen to take part in this study because of your professional role within the specialist palliative care service. We wish to involve all those who take part in discussions about referrals and admissions to the service, to enable us to explore how concepts of need for specialist palliative care are applied in practice.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you do 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 your work in any way.

What will happen to me if I take part?

We wish to gather information about need for care in two different ways.

Firstly, the researcher will sit in on team meetings to observe discussions surrounding referrals made to the service. The researcher will not be an active participant in these meetings, but will simply take notes on aspects of patients' needs for the service, as they are discussed. If all those present at each meeting consent, the researcher will also tape-record these meetings. These recordings will be transcribed and analysed to provide further detail on the important domains of need for care. In this part of the study, you will not be required to do anything outside of or in addition to your normal day-to-day responsibilities.

In the second part of the study, the researcher will conduct face-to-face interviews with a selection of those who participate in the team meetings which have been observed. The purpose of these interviews is to probe in more detail how providers conceptualise need for their services. If you are approached to be interviewed, we will ask you to sign a further consent form. All information given during these interviews will be kept strictly confidential, and no names will be attached to the information provided. The interview will be conducted at a convenient time and place of your choosing. It will cover your views on need for specialist palliative care in cancer patients, and how this might differ from need for generalist palliative care. The interview should last for around thirty minutes. Interviews will be tape-recorded, if you consent, and transcribed.

What are the possible disadvantages and risks of taking part?

We realise that you have limited time available to you, and participation in this study will require your time for about half an hour to an hour.

What are the possible benefits of taking part?

By feeding back the results to participating specialist palliative care providers, we hope that this project will enhance understanding of how specialist palliative care needs of patients with cancer can be consistently defined and measured. The information gathered from this stage of the project will be used in a cohort study of lung cancer patients looking at variations in use of specialist palliative care.

Will my taking part in this study be kept confidential?

All information which is collected from you during the course of the research will be kept strictly confidential. Transcripts of meetings and interviews will have your name removed so that you cannot be recognised from them. Tape recordings will be stored securely in the University, and destroyed immediately after analysis has been completed. In publications and reports, the identity of participating palliative care services will not be revealed, although basic descriptive information about the service will be given.

What will happen to the results of the research study?

A summary of the findings of the study will be sent to all participants on completion of the research, likely to be at the end of 2005. Results will also be published in peer-review journals. Participating specialist palliative care providers and staff will not be identified in any report or publication arising from this study.

Who is organising and funding the research?

This project is being funded by the Medical Research Council (MRC). It is being conducted by researchers from the London School of Hygiene and Tropical Medicine.

Who has reviewed the study?

The study has been reviewed and approved from an ethical point of view by Bromley Local Research Ethics Committee.

Your contacts

Jenni Burt is the researcher who will be conducting the observation and interviews. If you have any concerns about any aspect of the study please do get in touch and I will be happy to answer any questions.

Jenni Burt
Research Fellow
UCL Department of Epidemiology and Public Health
1-19 Torrington Place
London
WC1E 6BT

Phone: 020 7679 8283
Email: jenni.burt@ucl.ac.uk

CONSENT FORM

Title of Project: Defining need for specialist palliative care:
Non-participant observation

Name of Researcher: Jenni Burt

Please initial box

1. I confirm that I have read and understand the information sheet dated 18/02/05 (version 1) 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 work or legal rights being affected.
3. I understand that all the information I provide for the purposes of this study will be kept strictly confidential.
4. I consent to the meetings being taped, and understand that these tapes will be stored securely and destroyed after analysis is complete.
5. I agree to being quoted anonymously in the results
6. I agree to take part in the above study

Name of Participant Date Signature

Researcher Date Signature

CONSENT FORM

Title of Project: Defining need for specialist palliative care:
Interview

Name of Researcher: Jenni Burt

Please initial box

1. I confirm that I have read and understand the information sheet dated 18/02/05 (version 1) 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 work or legal rights being affected.
3. I understand that all the information I provide for the purposes of this study will be kept strictly confidential.
4. I consent to the interview being taped, and understand that this tape will be stored securely and destroyed after analysis is complete.
5. I agree to being quoted anonymously in the results
6. I agree to take part in the above study

Name of Participant Date Signature

Researcher Date Signature

Conceptualising need for specialist palliative care

Interview topic guide

FOR: Staff of specialist palliative care providers (medical, nursing, social work, professions allied to medicine, administrative, and other) who participate in decisions about services to offer to patients referred or made known to their service.

ADMINISTRATION: Face-to-face in a private, convenient place of the participant's choosing.

Interview to be conducted following the receipt of written consent to participate.

Introduction

This interview is taking place as part of a project exploring concepts and definitions of need for specialist palliative care. We are very interested to know your views about cancer patients' needs for specialist, rather than generalist palliative care, and which aspects of need you feel are particularly important.

With your permission, this interview will be tape-recorded. This helps us to ensure that we have an accurate record of everything you say. If you would prefer that this interview is not tape-recorded, that is absolutely fine – I will make hand-written notes instead. All the information you give to us will be kept strictly confidential, and your name will not be attached to the transcript of or notes from this interview.

Please remember, you are free to withdraw at any time from this interview – just tell me if you wish to stop. Also, if there is a particular question you do not wish to answer, please let me know.

Do you have any questions before we start?

[Ensure have obtained valid consent form including written permission to audio tape interview, if appropriate]

[Notify the participant that the tape has been switched on and is recording]

Introductory topic

- Participant's role in the palliative care service
Briefly cover: Involvement in patient care
Involvement in referral/admissions decisions
Other major areas of responsibility

Topic one: Definitions

- Participant's definitions of palliative care
Cover: Palliative care as a whole
Specialist palliative care – what type of care is this?
Generalist palliative care – what type of care is this?

Topic two: Referrals and admissions

- Participant's views on accepting referrals to specialist palliative care
Cover: Factors important in deciding to accept referral
Factors important in deciding to reject referral / inappropriate referrals
Probe: *Relative importance of:*
Diagnosis *Prognosis*
Symptoms *Functional status*
Psychosocial issues *Place of care*
Informal carers *Availability of*
resources *Other services*
Demographics *involved*
involved *Source of referral* *Other issues arising*
Source of referral *Other issues arising*

Topic three: Need for specialist palliative care

Following on from and further developing discussions around topics one and two:

- Role of specialist palliative care in cancer:
Cover: What does specialist palliative care offer to patients that other services don't?
How is it different from generalist palliative care?
How does it fit with other healthcare services a cancer patient might receive?
- Need for specialist palliative care:
Cover: What type of patients have need for specialist care?
Probe: *How might they benefit from this?*
Cover: What type of patients don't have need for specialist care?

Probe: Why wouldn't they benefit from this?

- Participants' conceptualization of need for specialist palliative care
Probe: Most important domains of need
- Any other comments

Topic four: Variations in need for specialist palliative care

Do you think that there may be occasions when a younger person has more need for specialist palliative care than an older person?

OR - switch

Do you think that there may be occasions when an older person has more need for specialist palliative care than a younger person?

End

Thank you for taking the time to participate in this interview. We shall ensure you receive a summary of our results arising from this work.

Do you have any further questions arising from this interview?

[Notify participant the tape recorder has been switched off and is no longer recording]

Appendix III

Critical appraisal of HRQL instruments

This appendix gives details of the 32 instruments I critically appraised but did not include in the short list for more detailed consideration of their use as an indicator of SPC need. The instruments are organised by target group (generic, cancer, lung cancer and palliative care) [Table 1]. I introduce the instruments, describe their appropriateness for use as an indicator of need for SPC, and then for each group summarise the outcome of my critical appraisal.

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
Generic instruments used in lung cancer or palliative care												
EQ-5D ³⁸⁶	5 dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) plus global QL item	Patient completion	3 statements to choose from in each dimension; plus VAS (0 to 100) for global QL rating	-	Test-retest correlation (general population) stated by authors to be "good".	Expert review. Pilot test.	Reasonable correlation with SF-36.	Changed in anticipated direction during treatment in breast cancer patients. ⁵²²	Time: 8-10 minutes. Acceptability: some low response rates in postal surveys.	Mainly postal surveys of community.	Healthy and ill adults, including lung cancer patients. All ages.	English and others.
Fox Simple Quality of Life Scale ³⁸⁷	25 items; four dimensions: satisfaction, well-being, health and functional status.	Patient completion	Five-point categorical scale	Overall Cronbach's α .93.	-	Literature review. Expert review. Patient interviews.	Correlated with FP-QLI, FACT-G, SF-36, General Well-being Scale.	-	Time: not stated. Acceptability: reading ease fine, low missing data	Community	Cancer patients from support group. Age not stated.	English
NHP (Nottingham Health Profile) ³⁸⁸	38 items; 6 domains: physical mobility, pain, social isolation, emotional reactions, energy, sleep.	Patient completion	Dichotomous yes/no	Overall Cronbach's α (older adults) .82. ⁵²³	Test-retest correlations for subscales (older adults) ranged from .81 to .97. n=93 Time=1 month ⁵²³	Patient interviews. Expert review. Pilot test.	Correlated with physical performance as predicted. ⁵²³	-	Time: 5 to 10 minutes. Acceptability: good.	Community. Outpatient.	Healthy and ill adults, including lung cancer patients. All ages.	English and others

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
SEIQoL (Schedule for the Evaluation of Individual Quality of Life) ^{389,390}	5 areas important to their QL listed by patient. Each area and overall QL rated. Finally, QL then rated for 30 hypothetical profiles.	Interviewer-administered	Visual analogue scale	Overall r = .90 ³⁸⁹	Test-retest correlation > .70.	Overall r ² = .88	-	-	Time: 40 minutes. Acceptability: Completed by 78% of patients.	Outpatient Inpatient	"Incurable" cancer. Age range 34 to 87.	English.
SEIQoL-DW (Schedule for the Evaluation of Individual Quality of Life – direct Weighting) ^{389,390}	5 areas important to their QL listed by patient. Each area and overall QL rated. Finally, 5 chosen areas weighted for importance.	Interviewer-administered	Visual analogue scale	Overall r = .90 ³⁸⁹	-	-	-	-	Time: 15 minutes. Acceptability: Completed by all patients.	Outpatient Inpatient	"Incurable" cancer. Age range 34 to 87.	English.

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
SF-36 (Short Form 36)	36 items; 8 domains: physical functioning, social functioning, role limitations due to physical problems; role limitations due to emotional problems mental health; energy/vitality, pain, general health perception	Self-administered.	Categorical scales (yes/no, 3-, 5- and 6-point).	Domain Cronbach's α (primary care population) .80 to .95 ⁵²⁴	Test-retest correlations ranged from .43 to .90. ³³⁷	Previous QL instruments.	Discriminant validity: differences in scores between well and unwell respondents. ⁵²⁴	Scores changed over time in expected direction for a number of diagnosis groups. ³³⁷	Time: 10-15 minutes. Acceptability: 78.5% of outpatient oncology patients completed all items. ³³⁷	Outpatient Inpatient Community	Healthy and ill adults, many cancer groups including lung cancer. All ages.	English plus others.
SIP (Sickness Impact Profile) ³⁹¹	136 items; 2 domains: physical and psychosocial covering 12 dimensions	Patient completion or interviewer-administered	Dichotomous (yes/no)	Overall Cronbach's α (non-cancer) .94. ³⁹¹	Test-retest correlation (non-cancer) .92. ³⁹¹		Correlated with clinical measures. (non-cancer) ³⁹¹	-	Time: 20 to 30 minutes. Acceptability: 5% patients refused participation. ⁵²⁵	Inpatient (cancer) ⁵²⁵	Advanced cancer. Mean age 59.2 ⁵²⁵	English

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
WHOQOL-100 ^{392,393}	100 items; 4 domains: physical health, psychological, social relationships, environment	Patient completion	Five-point categorical scale	Overall Cronbach's α .97: domains α .87 to .95. ³⁹³ Overall Cronbach's α (cancer) .97. ⁵²⁶	Test-retest correlations good (non-cancer). ⁵²⁷	Literature. Focus groups. Expert review. Pilot test.	Convergent and divergent validity between and within domains (non-cancer). ³⁹³ Discriminant validity: Inpatients poorer scores than others (non-cancer). ³⁹³ Scores different by cancer treatment and patient expressed condition. ⁵²⁶	-	Time not known. Acceptability not known	Outpatient Inpatient Community	Well adults and patients in 15 countries. ³⁹² Cancer patients aged <30 to >70. ⁵²⁶	English and others

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
WHOQOL-Bref ³⁹⁴	26 items; 4 domains: physical health, psychological, social relationships, environment	Patient completion	Five-point categorical scale	Domains: Cronbach's (non-cancer) α .68 to .82 ³⁹⁴	Test-retest correlations .66 to .87 for domains. n=391, time=2 to 8 weeks. (non-cancer) ⁵²⁸	Items taken from WHOQOL-100	Domain scores correlated with overall QL item. Discriminant validity: able to distinguish between patients and healthy adults.	-	Time: 5 minutes (well adults). Acceptability: < 1% missing data except for sex like (6%) and mobility (1.4%) (non-cancer). ³⁹⁴	Inpatient Outpatient Community	Healthy and ill adults, including patients receiving palliative care. Age range 12 to 97. ³⁹⁴	English and others
Cancer-specific instruments used in lung cancer or palliative care												
Care notebook ³⁹⁵	24 items; 3 domains: physical wellbeing, mental wellbeing and life wellbeing	Patient completion	11 point categorical scale	Domains Cronbach's α .86 to .93	Test-retest correlations .40 to .68 for subscales. n=249, time=4 weeks	Expert review. Pilot test.	Correlated with EORTC QLQ-C30 and FACIT-Sp-12. Discriminant validity: scores changed with performance status.	-	Time: Not known. Acceptability: not known.	Outpatient	Cancer patients, all stages. Age range <49 to >70.	Validated in Japanese. Translated to English

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
CARES (Cancer Rehabilitation Evaluation System) ³⁹⁶	Maximum 139 items. 6 domains: physical, psychological, medical interaction, marital, sexual, misc	Patient completion	Five-point categorical scale	Domains Cronbach's α .88 to .92	Test-retest correlations .84 to .95 for subscales. n=71, time=1 week	Literature. Interviews with patients. Expert review.	Correlated with SCL-90, KPS, DAS.	-	Time 10 to 45 minutes. Acceptability: majority "easy to use"	Inpatient Outpatient Community		English
CARES-SF (Cancer Rehabilitation Evaluation System – Short Form) ³⁹⁷	Maximum 59 items. 5 domains: physical, psychological, medical interaction, marital, sexual	Patient completion	Five-point categorical scale	Domains Cronbach's α .61 to .85	Test-retest agreement 86%	Expert review of CARES.	Correlated with the CARES and FLIC. Divergent validity: between domains.	Scores change over time (breast cancer patients 1, 7 and 13 months post diagnosis)	Time not known. Acceptability not known	Inpatient Outpatient Community	Cancer patients. All ages.	English
QOL-CS (Quality of Life Instrument – Cancer Survivor Version) ^{398,399}	41 items; 4 domains: physical wellbeing, psychological wellbeing, social wellbeing and spiritual wellbeing	Patient completion	Ten-point categorical scales	Overall Cronbach's α .93; subscales α .71 to .89	Test-retest correlations .89 overall; for subscales .81 to .90. n=70 time=2 weeks	Expert review	Correlated with FACT-G as expected.	-	Time not known. Acceptability not known.	Community	Cancer "survivors". All ages.	English.

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
QLI-C-FP (Ferrans and Power Quality of Life Index – Cancer version) ^{400;401}	66 items; 4 domains plus overall QL: health and functioning, socioeconomic, psychological/spiritual, family.	Patient completion	Six-point categorical scale	Overall Cronbach's α .95. Subscales α .66 to .93 ⁴⁰¹	Test-retest correlations whole index: .87 (non-cancer) time=1 week ⁴⁰⁰ . .78 (cancer) time=3 to 4 weeks. ⁵²⁹	Literature.	Convergent validity: correlated with a measure of satisfaction with life. Discriminant validity: able to distinguish between patients with less pain, depression and stress coping. Factor analysis demonstrated four sub-scales.	Not demonstrated in cancer; scores changed before and after intervention for e.g. cardiac patients.	Time: not known. Acceptability: not known.	Inpatient. Outpatient.	Breast and other cancer patients. All ages.	English.
FLIC (Functional Living Index – Cancer) ⁴⁰²	22 items; 5 domains: physical, psychological, social, family and symptoms	Patient completion	Seven-point visual analogue scale	Subscales Cronbach's α .65 to .87 ⁵³⁰	-	Panel review. Pilot test.	Correlated as expected with KPS, Katz ADL, GHQ and MPQ.	-	Time: Less than 15 minutes	Outpatient	Cancer patients	US English

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
Quick-FLIC ⁴⁰³	11 items; 5 domains: physical, psychological, social, family and symptoms	Patient completion	Seven-point categorical scale	Overall Cronbach's α .86	Test-retest correlations .76 overall. n=327, time=4 weeks	Expert review of FLIC	Correlated with FLIC, FACT-G and EORTC QLQ-C30. Discriminant validity: scores differed according to ECOG and treatment status.	Scores changed with declining ECOG status over 4 weeks.	Time not known. Acceptability not known.	Outpatient	Cancer patients. Mean age 48.4.	English and Chinese
Padilla's Quality of Life Index	14 items; 3 domains: symptom control, physical well-being, psychological wellbeing.	Patient completion	Visual analogue scale	Overall Cronbach's α .93	Test-retest correlations >.60.	-	Discriminant validity: scores varied between health adults and cancer patients.	-	Time: 5 to 10 minutes	Inpatient Outpatient	Cancer patients undergoing treatment plus healthy adults. Age not stated..	English
Rotterdam Symptom Checklist ⁴⁰⁴	38 items; 4 domains: physical symptom distress, psychological distress, activity level, and overall quality of life	Self completion	Four-point categorical scales	Domains α .71 to .86 (English sample)	-	Literature. Expert review.	Discriminant validity: differentiates between different disease and treatment states.	-	Time: Less than ten minutes. Acceptability: not known	Outpatient Inpatient Community	Cancer patients all stages	English plus other languages
Lung cancer specific instruments												

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
LCSS (Lung Cancer Symptom Scale) ⁴⁰⁵⁻⁴⁰⁷	9 items: symptoms plus summary items. Plus 6 item observer scale	Patient completion (initially interviewer-administered). Observer completion	Eleven-point categorical scale. ⁵³¹	Overall Cronbach's α .82	Test-retest correlations >.75 n=52, time=one hour	Expert review. Patient review.	Correlated with KPS, American Thoracic Society Questionnaire subscales, McGill Pain Questionnaire, Profile of Mood States, SIP	-	Time: 8 minutes.	Outpatient	Late stage lung cancer.	English.
Palliative care specific instruments												
AQEL (Assessment of Quality of Life at the End of Life Instrument) ⁴⁰⁸	19 items; 5 domains: physical, psychological, social, existential, medical care; plus global quality of life. 3 additional complementary questions.	Patient completion	Visual analogue scale marked 1 to 10	-	Test-retest correlations .52 to .90 for items. n=30, time=3 days	Literature. Clinical experience	Physical and psychological items correlated with CIPS. Poor correlation for social items. Total score correlated with KPS	Scores declined with approaching death.	Time not known. Acceptability not known	Community.	"Incurable" cancer. Age range 31 to 88.	Developed in Swedish.

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
Brief Hospice Inventory ⁴⁰⁹	17 items; 2 'sub-scales': symptoms and 'quality of life'	Patient completion; optional professional version	Ten-point categorical scale	Domains Cronbach's α symptom subscale .88; quality of life .94	Test-retest correlations .58 to .63 for subscales. N=145, time=1 week	Clinical experience	Factor analysis showed two sub-scales; symptoms and 'quality of life'.		Time not known. Acceptability not known.	Community	Patients under palliative care service. All diagnoses. Age range 37 to 98	US English.
EORTC QLQ-C15-PAL ⁴¹⁰	15 items; physical and emotional function, pain, fatigue, nausea/vomiting, appetite, dyspnoea, constipation, sleeping difficulties, overall QL.	Patient completion	Four- and seven-point categorical scales	-	-	Items from EORTC QLQ-C30. Chosen by interviews. Item response theory.	-	-	-	Inpatient Outpatient Community	Anticipated suitable for patients with advanced, incurable and symptomatic cancer.	English
HQLI (Hospice Quality of Life Index) ^{411;412}	28 items; 3 subscales: psychological, functional, social/spiritual wellbeing	Patient completion	Ten-point categorical scale	Overall Cronbach's α .88. Subscales α .82 to .84	-	Literature. Expert review. Interviews with patients.	Weak but significant correlation with ECOG. Discriminant validity: able to distinguish between cancer patients and healthy adults.		Time not known. Acceptability not known	Community	Cancer patients under palliative care service. Mean age 71.1	US English

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
Initial Assessment of Suffering in Terminal Illness ⁴¹³	43 items (reduced to 20 after testing); 5 domains: mood, symptoms, fears and family worries, knowledge and involvement, support	Patient completion or by interview	Five point categorical scale	-	Test-retest anova of mean scores no difference found. N=50, time= 3 to 5 weeks	Focus groups with experts. Pilot test.	Physical symptom domain correlated with Spitzer QLI	-	Time: 30 minutes. Acceptability: 95% of patients reported it to be "relevant"	Inpatient	Advanced cancer patients. Age not stated	English (Australian)
Missoula-VITAS Quality of Life index ³³⁹	25 items plus single-item global scale; 5 domains: symptoms, functional, interpersonal, well-being, transcendent	Patient completion	Five point categorical scale	Overall Cronbach's α .77	-	Expert review.	Correlated with the single-item QL measure. Divergent validity; poorly correlated with KPS.	-	Time not known. Acceptability: Completed by 87% of patients who had agreed to participate	Inpatient. Community.	Patients under palliative care service. All diagnoses. Age range 29 to 91	US English
POS (Palliative Care Outcome Scale) ⁴¹⁴	10 items; physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns, psychosocial needs.	Patient completion. Observer completion.	Five point categorical scale	Overall Cronbach's α .65.	Test-retest: proportion agreement within one score per item 0.74 to 1. n=34, time=varied.	Literature. Expert review. Patient interview. Pilot test.	Correlated with EORTC QLQ-C30.	Severe scores improved over time.	Time 7 minutes. Acceptability not known.	Inpatient. Outpatient. Community	Patients under palliative care services. Age range not known.	English.

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
PQLI (Palliative Care Quality of Life Instrument) ⁴¹⁵	28 items plus single-item global scale; 7 domains: activity, self-care, health status, choice of treatment, support, communication, psychological affect	Patient completion	Three point categorical scale	Overall Cronbach's α .79. Subscales α .77 to .92	Test-retest correlations .73 to .99 for items; for subscales .84 to .98	Literature. Expert review. Pilot test.	Correlated with ECOG, AQEL and EORTC QLQ-C30	-	Mean time 8 minutes.	Outpatient	Cancer patients under palliative care service. Age range 19 to 88	Validated in Greek. Translated to English.
Patient Evaluated Problem Score ⁴¹⁶	Unlimited list of problems; plus single-item global scale	Patient completion	Problems: rated on a three point categorical scale. Global QL: ten point categorical scale	-	-	-	-	-	A few minutes. Completed by 73% of admitted patients	Inpatient	Patients under palliative care service. Most cancer. Age unknown	English.

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
PNPC (Problems and Needs in Palliative Care) ³²⁸	138 items; 13 domains: activities of daily living, physical symptoms, role activities, financial issues, social issues, psychological issues, spiritual issues, autonomy, problems in consultations, quality of care, GP care, specialist care, informational needs	Patient completion	Each item asked if a problem (yes/somewhat/no) and if want help for this (yes, more/as much as now/no)	Domains Cronbach's α .67 to 0.89	-	Literature. Patient interviews. Expert interview. Pilot test.	Correlated with EORTC QLQ-C30 and COOP-WONCA charts.	-	Time: Not known Acceptability: Response by item ranged from 12% to 90%	Community	Cancer patients under palliative care. Age range 30 to 87	Validated in Dutch. Translated to English.
QUAL-E (Quality of life at the End of Life) ^{417,418}	26 items; 4 domains: life completion, relationship with health care provider, symptoms impact, preparation for end of life.	Interview-administered.	Five-point categorical scale	Domains Cronbach's α .68 to 0.87.	Test-retest correlations .23 to .74 for subscales. N=248, time=1 week	Focus groups and interviews with patients, carers, experts. Patient survey. Pilot test.	Correlated with FACIT-SP, Missoula-VITAS QOL Index and Participatory Decision Making as expected.	Not yet tested	Time: not known. Acceptability: not known.	Outpatient	Outpatients with advanced disease. Cancer and non-cancer. Age range 28 to 88.	English.

Table 1. Critical appraisal of HRQL instruments used in lung cancer and palliative care												
Instrument	Items and domains	Administration	Response format	Reliability		Validity		Responsiveness	Burden	Appropriateness		
				Internal consistency	Reproducibility	Content	Construct			Setting	Groups tested in	Language
Supportive Care Needs Survey ⁴¹⁹	61 items; 5 domains: psychological, health system and information, physical and daily living, patient care and support, sexuality.	Patient completion	Five-point categorical scale	Subscales Cronbach's α .87 to .97	-	Adapted from Cancer Needs Questionnaire. Expert review. Patient review.	Factor analysis identified five factors supporting underlying constructs	-	Time: 20 minutes. Acceptability: Minimum reading age.	Outpatient.	Cancer patients. Age range 18 to 85.	English (Australian)
Therapy Impact Questionnaire (Tamburini 1997)	36 items; 4 domains: physical symptoms, functional status, emotional and cognitive issues, social interaction	Patient completion, or observer completion	Four-point categorical scale	Not known	Not known	Literature. Expert review. Pilot test.	Not known	Not known	Time: Not known. Acceptability: 87% response rate.	Inpatient Outpatient Community.	Advanced cancer patients under palliative care service. Age not stated.	Validated in Italian. Translated to English.

Critical appraisal of generic instruments

Seven generic instruments, plus two additional shortened versions, were identified as having been used with lung cancer or palliative care patient populations, although their use was mainly confined to oncology rather than palliative care settings. These were the EQ-5D, developed by the EuroQol group; the Fox Simple Quality of Life Scale; the Nottingham Health Profile; the SEIQoL (Schedule for the Evaluation of Individual Quality of Life), and its shorter version the SEIQoL-DW; the SF-36; the Sickness Impact Profile; and the WHOQOL-100 and its shortened version the WHOQOL-Bref.

EQ-5D

The EQ-5D is a non-disease specific health outcome measure developed simultaneously in a number of European languages, including English.³⁸⁶ It is very brief, with only five questions (mobility, self-care, “usual activities”, pain/discomfort and anxiety/depression) and one rating of global health status, measured using a visual analogue scale. Whilst more widely used in surveys of the general population,⁵³² it has also been used to assess quality of life in lung cancer patients,⁵³³ particularly in the context of clinical trials (e.g.⁵³⁴). It has been criticised for having poor response rates, for being skewed, and for having poor sensitivity.³³⁷ p.13 The response statements for each dimension give only three options (for example, I have no problems in walking about, I have some problems in walking about, I am confined to bed). These may be inappropriate in disease-based research, leading to poor differentiation between respondents. The instrument has additionally been criticised for using a 0 to 100 score in its visual analogue scale for global health status; in one study 7.3 of respondents aged 75 and above failed to complete this “thermometer”; and 63.5% of respondents chose a score ending in zero, negating the assertion that a 0 to 100 scale enables greater score precision.⁵³⁵

Fox Simple Quality of Life Scale

Developed as a generic HRQL instrument, but validated in a cancer population, the Fox Simple Quality of Life Scale is a 25-item instrument covering satisfaction, wellbeing, health and functional status.³⁸⁷ Items do not include physical symptoms. It is still in the early stages of development and data on reproducibility and responsiveness has yet to be published.

Nottingham Health Profile

The Nottingham Health Profile, widely used in cardiovascular disease, has also on occasion been applied to lung cancer patient populations.⁵³⁶⁻⁵³⁸ This 38-item instrument covers physical mobility, pain, social isolation, emotional reactions, energy and sleep, using a dichotomous (yes/no) response format. This format has been criticised for restricting the available answer options to only yes or no, with no grading of e.g. severity – leading to lower response rates and a high proportion of missing data.⁵³⁹ Of particular concern to this study, there is evidence that the domains of pain and mobility are not distinct, with many pain questions set in the context of mobility (e.g. “I’m in pain when I walk”).^{540;541} For lung cancer patients, pain may be present regardless of movement – items on pain must take this into account to be relevant.

SEIQoL/SEIQoL-DW

The SEIQoL and SEIQoL-DW ask respondents to nominate five domains important to their quality of life; the weighting system varies according to whether the long or short form is used. The SEIQoL was first used in gastroenterology and hip replacement patients and demonstrated good acceptability and validity.^{542;543} Its suitability for use in oncology and palliative care patients is disputed; whilst some authors claim that it is best restricted to relatively healthy individuals, others have reported good

feasibility in patients with palliative care needs. ^{389;544;545} The instruments must be interviewer-administered and their length and complexity mean their practicality in larger scale studies is poor. ³⁹⁰

SF-36

The SF-36 is one of the most widely used generic HRQL instruments, with well recorded reliability and validity across disease groups. It includes 36 items in 8 domains, covering physical and social functioning, role limitation, mental health, energy, pain and perception of general health. It has been used in a number of studies of lung cancer patients, ⁵⁴⁶⁻⁵⁴⁸ but its use in palliative care has been less well documented. As a generic instrument, it covers few symptoms aside from pain.

SIP

The Sickness Impact Profile is a 136 item, self- or interviewer-administered instrument covering physical and psychological domains. Its psychometric properties in cancer are uncertain, despite its widespread use in other clinical areas. ³⁹¹

WHOQOL-100 and WHOQOL-Bref

The WHOQOL-100 is a reliable and valid instrument developed and tested simultaneously in 15 countries, including the UK. ^{392;393;527} Its use in cancer patients was validated in Japan, although its acceptability in advanced cancer patients is unreported. ⁵²⁶ The WHOQOL-Bref is a 26 item version recently developed to reduce respondent burden; its use within lung cancer or palliative care has yet to be reported. ³⁹⁴

Generic instruments – summary

Whilst some of the generic instruments reviewed above are extensively used within cancer research, particularly the SF-36, there are a number of limitations to their use as an indicator of need for palliative care. Firstly, their ability to discriminate between lung cancer patients with and without a need for specialist palliative care is likely to be low; few include symptoms other than pain and few have fine enough response formats to generate a range of responses in this group. Secondly, despite their use in lung cancer trials, the inclusion of domains such as work or the ability to walk long distances is redundant when applied in advanced disease. Thirdly, few include domains specific to the assessment of need for specialist palliative care, such as existential issues including concepts self, death and dying, and meaning of life. For these reasons, none were short listed for further consideration.

Critical appraisal of cancer-specific instruments

Eight cancer-specific HRQL instruments, and two additional shortened versions, were identified for full critical appraisal. The shortlisted instrument in this group was the EORTC QLQ-C30 (European Organization for Research and Treatment of Cancer Core Quality of Life questionnaire), described in full in Chapter 6. The non-shortlisted instruments were the Care Notebook; CARES (the Cancer Rehabilitation Evaluation System) and its short form CARES-SF; the Quality of Life Instrument – Cancer Survivor Version;; the Ferrans and Power Quality of Life Index – Cancer version; FLIC (the Functional Living Index-Cancer) and its short form Quick-FLIC; the Multi-dimensional Quality of Life Scale – Cancer (MQOLS-CA); and the Rotterdam Symptom Checklist.

The Care Notebook

The care notebook is a 24-item HRQL instrument designed primarily for clinical, rather than research use.³⁹⁵ Reliability and validity were tested in a population of Japanese cancer outpatients; whilst it has been translated into English, it has not been psychometrically tested in this language.

CARES and CARES-SF

CARES (139 items) and the more widely used short form CARES-SF (59 items) are reliable and valid instruments developed to measure the rehabilitation needs of cancer patients.^{396,397} Respondents are asked to rate a list of cancer-related problems they might encounter on a daily basis, including physical changes and marital relationships. The use of CARES in advanced cancer patients has been questioned due to its inclusion of items on work and sexual activity, deemed to be inappropriate in this population, as well as its length.⁵⁴⁹ Additionally, the instrument is commercially licensed and a fee must be paid to use it within research studies; for this reason, the full item wording is difficult to obtain for assessment purposes.

The Quality of Life Instrument – Cancer Survivor Version (QOL-CS)

The QOL-CS was developed by researchers at the City of Hope National Medical Center in the USA to assess physical, psychological, social and spiritual wellbeing.^{398,399} It is aimed mainly at “cancer survivors” – those who have received successful treatment for an incidence of cancer – and includes items such as the extent to which respondents are fearful of a recurrence or spread of cancer. This limits its application to patients at all stages of cancer.

FLIC and Quick-FLIC

Another widely-used instrument is the 22-item FLIC,⁴⁰² which also has a shortened version, the Quick-FLIC. The FLIC has been criticised for using visual analogue scales as its response format, which not all patients find easy to use.³³⁷ The Quick-FLIC, validated in English and Chinese speaking cancer patients in Hong Kong, adapted a categorical scale response format for this reason.⁴⁰³ However, the major concern for this study is the reported problems in its use with lung cancer patients – with low response rates and a lack of relevant functional and psychosocial items.^{337;550}

Padilla's Quality Life Index

The 14 item Quality of Life Index developed by Padilla and colleagues is aimed at cancer patients undergoing treatment, and was validated in adults receiving chemotherapy or radiotherapy. It has not been tested in patients with advanced cancer and its suitability for application in patients at all stages of disease therefore remains uncertain.

The Rotterdam Symptom Checklist

The Rotterdam Symptom Checklist is a 38 item instrument developed for cancer patients, covering physical symptoms, psychological distress, activity level and overall quality of life. It has good psychometric properties, but its focus on symptoms and functional status to the exclusion of the social and spiritual dimensions of quality of life raises concerns over its coverage of health-related quality of life, rather than just physical symptoms.⁵⁴⁹ Additionally, it has been found to have very low acceptability and completion rates in inpatient hospice patients.⁵⁵¹

Cancer-specific instruments – summary

Of the cancer-specific instruments reviewed, the CARES, the QOL-CS and Padilla's Quality of Life Index have not proved suitable for administration in advanced cancer patients, limiting their utility in a cross-sectional survey of all stages of disease. The FLIC and Rotterdam Symptom Checklist excluded a number of important dimensions of HRQL, particularly psychosocial items. Finally, the Care Notebook has not been psychometrically tested in English speaking populations and is thus unsuitable for use until its validity and reliability have been confirmed in this language.

Lung-cancer specific instruments

Three lung-cancer specific instruments were identified; the EORTC QLQ-LC13 (part of the EORTC modular HRQL system), the Functional Assessment of Cancer Therapy – Lung (FACT-L), part of the Functional Assessment of Chronic Illness Therapy (FACIT) measurement system; and the Lung Cancer Symptom Scale (LCSS). Two of these – the EORTC QLQ-LC13 and the FACT-L were shortlisted for full content appraisal. The LCSS is briefly discussed below.

LCSS

Designed for repeated use within the context of clinical trials, the LCSS is a very brief scale comprising only 9 items.^{405;407} Its focus is on symptoms (appetite loss, fatigue, cough, dyspnoea, haemoptysis, pain), with only summary items of other aspects of quality of life (total symptom distress, normal activity status and overall quality of life). An alternative response format for the LCSS was recently developed, enabling a choice between the original visual analogue scale or a categorical scale, appropriate for the computer scanning of instruments often used in large scale trials. Psychometric properties of the instrument remained adequate with this

change in format.⁵³¹ The VAS approach requires initial interviewer administration to explain the response format; the categorical format was also administered in this way. The LCSS is commercially copyrighted, and a fee is payable for its use. Advantages include its brevity, and it has proved suitable for use in patients with advanced disease.

Lung-cancer specific instruments – summary

The LCSS, whilst it has shown good reliability and validity, is limited in its coverage of non-symptom concerns, which were shown to be important in the ethnographic study undertaken. It additionally relies on being interviewer-administered; for these reasons it does not appear suitable to use in the planned cross-sectional survey.

Palliative care specific instruments

The largest group of instruments identified were developed for use specifically in palliative care populations. However, this group also showed the greatest variation in the extent to which instruments had been psychometrically tested, with some showing little or no evidence of their reliability and validity.

Assessment of Quality of Life at the End of Life

The Assessment of Quality of Life at the End of Life instrument comprises 19 items with a VAS response format.⁴⁰⁸ Tests on validity showed there were problems with the social domain; internal consistency has not been reported. It was originally validated in Swedish; whilst it has been back-translated to English its properties in this language are unknown.

Brief Hospice Inventory

Developed specifically for patients receiving palliative care, each of the 17 items in the Brief Hospice Inventory uses a ten-point categorical scale anchored by opposing descriptors (e.g. No pain / worse possible pain).⁴⁰⁹ It has reasonable psychometric properties and is quick to complete. However, the inclusion of items such as “hospice has been of greater help than I could have imagined /no help at all” preclude its use in patients not receiving palliative care.

EORTC QLQ-C15-PAL

A shortened version of the EORTC QLQ-C30, this instrument has been developed specifically for palliative care populations.⁴¹⁰ It is still in its early stages of psychometric testing, although items were taken systematically from the robustly evaluated longer core instrument. As the authors explain, its utility is likely to be in patients with particularly symptomatic progressive cancer who are unable to complete the QLQ-C30, which already has demonstrated acceptability in advanced cancer patients.

Hospice Quality of Life Index

Devised for and validated in hospice patients in the USA, the Hospice Quality of Life Index covers three domains of HRQL: psycho physiologic well-being, functional well-being and social and spiritual well-being. It has been found to have internal consistency and construct validity, but its reproducibility and responsiveness have not been tested.^{411;412} As with the Brief Hospice Inventory, however, its inclusion of questions related to the hospice care respondents are receiving precludes its administration to patients who are not under palliative care.

Initial Assessment of Suffering

Aimed at patients with advanced cancer, the Initial Assessment of Suffering instrument covers mood, symptoms, fears and family worries, knowledge and involvement and perceived support.⁴¹³ A 43-item version was initially tested and limited data on reliability and validity given. As a result of these tests the instrument was reduced to 20 items, but psychometric data on the shortened version has not been published.

Missoula-Vitas Quality of Life Index

The Missoula-Vitas Quality of Life Index was developed for use in terminally ill patients and originally validated in a hospice population.^{339;552} The five domains (across 26 items) of the instrument cover symptoms, function, interpersonal, wellbeing and spirituality. Whilst it has good psychometric properties for palliative care patients, it is not suitable for use in earlier stages of disease; for example, items include “As the end of my life approaches, I am comfortable with the thought of my own death/I am uneasy with the thought of my own death.” Additionally, it does not cover the assessment of symptoms in detail.

Palliative Care Outcome Scale (POS)

POS was developed in the UK as an outcomes measure for palliative care services.⁴¹⁴ It has ten items covering physical and psychological symptoms and practical issues such as time spent waiting for hospital appointments, over a time scale of the previous three days. A corresponding instrument is available for completion by health care professionals. It has demonstrated adequate psychometric properties in patients under palliative care services, but its application and relevance to wider groups of cancer patients is uncertain. Additionally, its content in relation to assessment of symptoms – a key indicator of need for specialist palliative care – is limited.

Palliative Care Quality of Life Instrument

The 28-item Palliative Care Quality of Life Instrument was developed and validated in another language (Greek) and translated to English for publication.⁴¹⁵ Whilst the authors reported it to have good reliability and validity, testing has not been extensive and its responsiveness and applicability in all settings of palliative care are unknown. Additionally, an examination of the English language version raises questions about the quality of the translation, and the instruments comprehensibility to English palliative care populations.

Patient Evaluated Problem Score

The Patient Evaluated Problem Score is similar to the SEIQoL in being a patient-led instrument in which they are able to list and rate the problems they are facing.⁴¹⁶ It has proved acceptable to even very ill hospice inpatients, and is used in clinical practice within the UK, but has undergone no psychometric testing. It is therefore not suitable to use as a HRQL instrument within research studies.

Problems and Needs in Palliative Care (PNPC)

Developed and validated in Dutch, and subsequently translated to English, the Problems and Needs in Palliative Care instrument covers 138 items of both quality of life and quality of care.³²⁸ It has not been psychometrically tested in English.

QUAL-E (Quality of Life at the End of Life)

A recently developed measure of HRQL in patients with life-threatening illness, the 31-item QUAL-E has reasonable psychometric properties in patients with advanced disease.^{417;418} It covers life completion, relationships with health care providers, the impact of symptoms and preparation for end

of life. However, domains are slanted in particular towards US hospice patients, who have enrolled in a very specific program of terminal care. It is designed to be administered by an interviewer.

Supportive Care Needs Survey

The Supportive Care Needs Survey is a combined health-related quality of life and quality of care instrument, developed and validated in Australia. Its domains cover psychological, health system and information, physical and daily living, patient care and support and sexual issues over 61 items. It has been validated in outpatient clinics settings with cancer patients in Australia, but has not been tested on UK populations.

Palliative-care specific instruments – summary

Instruments developed for use in palliative care populations varied widely in their content. A number – such as the Missoula-Vitas QLI and the Hospice Quality of Life Index – include items very specific to patients with a terminal illness, and are therefore unlikely to be suitable for use in patients in earlier stages of cancer. Furthermore, instruments were frequently poorly psychometrically tested, with little evidence of reliability and validity.

Appendix IV

Pilot study of equity of use of specialist palliative care

This appendix contains full details of the methods and results of the pilot survey I conducted prior to the commencement of the main cross-sectional survey of lung cancer patients. The pilot had the following objectives:

1. To establish the study within participating clinics and raise awareness amongst all staff.
2. To pilot the anticipated method of recruitment and gain information on expected recruitment rates.
3. To assess the clarity, acceptability and feasibility of the patient and carer questionnaires developed for the study.
4. To assess the comprehensiveness and ease of use of the medical record data extraction form developed for the study.

The methods and results of this pilot are reported in full below.

Pilot sample

A convenience sample of patients with a diagnosis of lung cancer attending two of the four participating lung cancer outpatient clinics, and their carers, were approached.

Recruitment and consent

On arrival in the clinic, patients and carers attending with them were approached to introduce the study. I explained the study and the pilot process, and gave patients and their carers a study information pack containing an information sheet, consent form and the study questionnaire. Patients and carers were asked to read through the information about the

study and, if they wished to participate, complete the consent form and study measures whilst in the clinic.

During this pilot period, I noted the number of people I approached, the number who agreed to take part in the pilot, and the responses of those approached who chose not to participate. I also kept notes on the running of the clinic, the opportunities for approaching potential participants, and the barriers to recruitment.

Pilot patient questionnaire

The patient questionnaire was compiled for the purposes of this study. In four sections, questions covered:

1. Diagnosis
2. Use of health care services for this diagnosis, including SPC services
3. HRQL (as an indicator of need for SPC)
4. Personal details

The first two sections, covering the patient's stated diagnosis and other illnesses, and their use of health care services for lung cancer, were devised for this study. The use of health care questions covered patients' contacts with nurses, doctors, (including those from SPC services), and professions allied to medicine for the treatment and care of their lung cancer. It also asked whether they had sought further information on their diagnosis from literature, the internet or telephone advice lines. In the piloted version of the questionnaire, the HRQL instrument used was the McMaster Quality of Life Instrument, chosen using methods described in full in Chapter 6 [see end of Appendix for text]. Finally, the personal details section was based on

questions used in a National Survey of NHS Patients developed by the Picker Institute and others.⁴⁵¹

Prior to piloting, the draft questionnaire, information sheet and consent form were sent to four cancer patients recruited through the CancerVOICES 'Opportunities for involvement' scheme for their comments. The questionnaire was slightly adapted following their feedback, with some amendments made to question wording (no amendments in wording or layout were made to the validated HRQL instrument).

Pilot carer questionnaire

A brief instrument was also developed for family and friends attending clinics with participating patients. This comprised three sections:

1. Relationship with and help given to the attending patient
2. The General Health Questionnaire 12 item version (GHQ-12)
3. Respondent's personal details.

Pilot medical records data extraction form

A form was developed to obtain data from participants' medical records in a standardised format [appendix V]. Participating clinics maintain written, hospital-based notes for each patient, which were used to gather further information on demographic details, diagnosis and subsequent disease progression, treatment received (surgery, radiotherapy, chemotherapy), past medical history, and recorded use of SPC.

Questionnaire and data extraction form piloting

Whilst patients and carers were completing the questionnaire, I timed length of completion, and answered any questions as they arose. Once the

questionnaires were completed, I undertook a brief interview with participants to address the following questions:

1. Did they understand the purpose of the research?
2. Were the questionnaire instructions clear?
3. Were any questions unclear or ambiguous?
4. Were any questions missing?
5. Did they object to answering any questions?
6. Was the layout clear and attractive?
7. Did they understand how to return the questionnaire?

Completed questionnaires were entered onto the pilot database to check for suitability of coding and data entry procedures.

For a sub-sample of the patients who took part in the questionnaire piloting, I explored the process of accessing and extracting data from their medical notes using the standardized form developed for this purpose.

Results of pilot study

Recruitment

18 patients and 17 carers were approached to participate in the pilot study. There were no patient refusals to participate; one carer refused to participate, and one patient attended clinic alone. The pilot study was therefore based on 18 patients and 16 carers. Recruitment procedures were piloted in full at one clinic session; 13 of 14 patients booked to attend clinic did so, and all 13 attending patients were recruited to the study and completed the questionnaire whilst in the clinic.

Participants

Descriptive statistics obtained from the pilot survey are shown in Tables 1 and 2.

Table 1. Pilot study results: patients	
	n (%)
Age	
< 55	3 (16.7)
55 to 64	3 (16.7)
65 to 74	7 (38.9)
≥ 75	5 (27.8)
Gender	
Male	7 (38.9)
Female	11 (61.1)
Diagnosis	
SCLC	3 (16.7)
NSCLC	10 (55.6)
Unknown	5 (27.8)
Date diagnosed	
In the past month	1 (5.6)
In the past three months	2 (11.1)
In the past six months	4 (22.2)
More than six months ago	11 (61.1)
Reported use of SPC	
From questionnaire	10/18 (55.6)
From notes audit	3/13 (23.1)
HRQL score	
Range	118 to 221
Mean	163 (sd 31)
Quartiles	
25	140.25
50	163.00
75	190.25

Table 2. Pilot study results: carers	
	n (%)
Age	
< 45	3 (18.8)
45 to 64	9 (56.3)
65 to 74	4 (25.0)
≥ 75	0 (0.0)
Gender	
Male	6 (37.5)
Female	10 (62.5)
Relationship to patient	
Husband/wife/partner	6 (37.5)
Son/daughter	7 (43.8)
Other family member	1 (6.3)
Friend	2 (12.5)
Number of children in household	
0	13 (81.3)
1 to 2	2 (12.5)
3 or more	1 (6.3)
GHQ score	
0 to 3	5 (35.7)
4 or more	9 (64.3)

Patient questionnaire

Sections A (reason for hospital visit), B (your use of health care) and C (personal details) of the patient questionnaire were completed in full by all patients, apart from one missing response to the question asking about contact with a palliative care doctor. However, 25 of 32 items in the HRQL scale had missing values. The highest proportion of missing values was 5/18 (28%) for mobility, and 4/18 (22%) for both oedema and employment, with an overall missing value percentage of 8% (45/576). Only 8/18 (44%) of respondents completed all items on the scale.

Difficulties with the HRQL scale were as follows:

1. Patients did not understand how best to rank their situation using the 1 to 7 scoring system, and frequently asked for assistance.
2. A number of participants felt that the instrument included inappropriate questions. For example, a question on mobility uses an anchor which states “bedridden”, which is not relevant to an outpatient population. Additionally, many respondents were retired, with no such option given by the “employment” question.
3. Responses to a large number of items were poorly distributed, and skewed towards extreme scores (e.g. 41% of respondents scored 7 for pain). Whilst this may reflect the clinical reality of this population, it is also possible that difficulties with the scale led respondents to use either anchor (1 or 7) as their responses – a phenomenon noted on several completed questionnaires.

39% (7/18) patients had assistance from their family or friends in completing the questionnaire. The time taken for patients to complete the whole questionnaire ranged from approximately 10 to 30 minutes.

Carer questionnaire

Sections A (reason for hospital visit) and C (personal details) of the carer questionnaire were well completed. Section A had only 2 responses missing overall, both for the same respondent; these related to living with and looking after the patient. Discussion with the respondent clarified the reason for non-completion was the complexity of the situation between her and her husband (the patient). Section C had no missing items. Section B, the GHQ-12, was not completed by two respondents. Both were friends, rather than relatives, of the patient. One felt it would not produce relevant results as she was herself ill, having recently had surgery; it was not possible to clarify

with the other respondent the reason for not completing this section. Of the remaining 14 respondents, 2/168 items were missing from the GHQ (1.2%).

There were no reported problems for the carers in completing the questionnaire; average time of completion was five minutes.

Medical notes data extraction form

The data extraction form designed for use with patient's medical records was found to be comprehensive in its content, but the layout was not always appropriate to the information being extracted. For example, there was no space to accurately record the development of the disease. These were particularly important data as stage at diagnosis was frequently different to the disease stage at the time the respondent participated in the study.

There were discrepancies between patient report and medical records on SPC use. According to responses on the patient questionnaire, 56% had used SPC services; from medical records data this figure was 23%. It was decided prior to the pilot that if there were inconsistencies between patient report and medical records, use would be determined based on medical records alone, as patient recall and recognition of SPC input was unlikely to be as reliable. However, the level of inconsistency gave rise to the question of whether either source was an accurate record of use of SPC.

Pilot conclusions and changes made to study design

As a result of the pilot, I determined that recruitment of patients could be undertaken successfully within the clinic setting, with a high participation rate (at pilot 100% of patients and 94% of carers approached). However, there were three major areas of concern in which changes were made to the planned study design.

Firstly, the HRQL instrument chosen as an indicator of patients' need for SPC, the McMaster Quality of Life Instrument, proved unsuitable in this population. One of the reasons for the original choice of the McMaster over the EORTC instruments (which also relate closely to the identified domains of need for SPC) was the ability to calculate a summary score to be used in the analysis of use in relation to need. The EORTC instruments, by contrast, do not enable the calculation of a summary score derived from all items, although a global quality of life score can be derived from items on overall quality of life and health. However, the EORTC QLQ-C30 and LC13 are used extensively in cancer research, and have excellent psychometric properties.

I therefore decided to use the EORTC-QLQ C30 and LC-13 as the indicator of need for SPC, with the global quality of life score as the primary explanatory variable of interest. The revised questionnaire including the EORTC instruments was piloted in a further two patients. No problems were identified, and additional piloting of the revised questionnaire was not undertaken due to the extensive use of the EORTC in the UK outpatient setting. Other sections of the questionnaire remained unchanged following the pilot study.

Secondly, during the pilot a number of patients required or requested physical assistance to complete the study instruments. I therefore decided to offer assistance with questionnaire completion where necessary in the main study. To accomplish this, verbal explanation of the study would stress the importance of participants answering questions themselves, whilst stating that questions could be read out, and answers written down, by a carer or the researcher. In this way, eligible patients who were physically unable to complete a questionnaire would be offered the opportunity to participate.

Finally, I resolved the issue of accurate outcome ascertainment. As previously described, during the course of piloting I found discrepancies between SPC use reported by patients and recorded within hospital notes. In addition, my review of notes for patients receiving care at the cancer centre found that these were often sparse, with little detail of previous or current care.

To ensure complete ascertainment of the outcome, I decided that use of SPC in the final analysis would be determined directly from SPC providers' records, rather than from hospital notes or patient report. As I would have written consent from all participants to access their medical records, I approached all SPC providers in the study area to ask if they would check their records to determine whether patients had been under their care or not at the time of their study participation. All providers agreed with this request.

McMaster Quality of Life Questionnaire

Many people experience changes in one or more areas of their lives during their illness. Below, please describe how you have generally felt during the last week. Please circle the number that best describes your experience for each item.

If your illness causes no problems in this area, that is no change has occurred due to your illness, please check the box under "Does Not Apply" and do not rate the item.

Does Not Apply			Rating of your experience (Circle one number for each area please)							
<input type="checkbox"/>	Pain	Seldom	1	2	3	4	5	6	7	Almost constant
<input type="checkbox"/>	Appetite	Normal	1	2	3	4	5	6	7	No appetite
<input type="checkbox"/>	Insomnia (Sleeplessness)	None	1	2	3	4	5	6	7	Major problem/unable to sleep
<input type="checkbox"/>	Nausea	Cannot stand the sight of food	1	2	3	4	5	6	7	Not nauseated
<input type="checkbox"/>	Restlessness	Very agitated	1	2	3	4	5	6	7	Normal
<input type="checkbox"/>	Breathing	Very short of breath	1	2	3	4	5	6	7	Not short of breath
<input type="checkbox"/>	Pain	Very mild/no pain	1	2	3	4	5	6	7	Severe
<input type="checkbox"/>	Diarrhoea	None	1	2	3	4	5	6	7	Frequent
<input type="checkbox"/>	Vomiting	Never	1	2	3	4	5	6	7	Very often
<input type="checkbox"/>	Cough	Severe, persistent coughing spells	1	2	3	4	5	6	7	Seldom cough
<input type="checkbox"/>	Oedema (swelling)	None	1	2	3	4	5	6	7	Unable to move normally
<input type="checkbox"/>	Constipation	Severe	1	2	3	4	5	6	7	None
<input type="checkbox"/>	Sore Mouth	Severe	1	2	3	4	5	6	7	None
<input type="checkbox"/>	Employment	Unable to work	1	2	3	4	5	6	7	Maintain previous employment

Please turn over to the next section

**Rating of your experience
(Circle one number for each area please)**

Mood	Not depressed	1 2 3 4 5 6 7	Very depressed
Fatigue/tiredness	Usual energy/Not tired	1 2 3 4 5 6 7	Exhausted
Mobility	Bedridden	1 2 3 4 5 6 7	Normal activities (pre illness)
Interest in Others	Very interested	1 2 3 4 5 6 7	Not interested
Future planning	Limited to days	1 2 3 4 5 6 7	Months or more
Confusion	Never confused	1 2 3 4 5 6 7	Very often confused
Drowsiness	Not drowsy	1 2 3 4 5 6 7	Very drowsy
Meaning of life	Find life very meaningful	1 2 3 4 5 6 7	See no purpose
Anxiety	Very anxious	1 2 3 4 5 6 7	Not anxious
Well-being	Calm/relaxed	1 2 3 4 5 6 7	Very worried and fearful
Concentration	Cannot concentrate	1 2 3 4 5 6 7	Usual / normal
Appearance	Getting worse	1 2 3 4 5 6 7	Improving
Personal comfort	Very uncomfortable	1 2 3 4 5 6 7	Comfortable
Household management	Participate as usual	1 2 3 4 5 6 7	Cannot take part
Social interaction	Very limited	1 2 3 4 5 6 7	Interact daily with relatives/friends
Self care	Independent	1 2 3 4 5 6 7	Must rely entirely on others
Decision making	Take part actively	1 2 3 4 5 6 7	Completely rely on others
<hr/>			
Overall, your quality of life	Very poor	1 2 3 4 5 6 7	Excellent

Appendix V

Documentation for cross-sectional survey of lung cancer patients and carers

This appendix contains the documentation used in the cross-sectional survey of lung cancer patients and carers, investigating equity of use of specialist palliative care in relation to age. This comprises:

- Patient information sheet
- Patient consent form
- Patient questionnaire
- Carer information sheet
- Carer consent form
- Carer questionnaire
- Medical notes data extraction form

The use of health care services study

Participant Information Sheet

I would like to invite you to take part in a research study. Please take time to read the following information carefully and discuss it with others if you wish.

My name is Jenni Burt and I am a researcher supported by a grant from the Medical Research Council. I work for University College London (UCL). Please ask me if there is anything that is not clear or if you would like more information.

Thank you for reading this.

Purpose

In this study we would like to find out more about what type of health care patients with lung illnesses receive. We want to know if there are differences between particular groups of patients in the care they receive, and why this might be happening. It is important for us to include family members and friends, as well as patients, in this study so we can know how the treatment and care patients receive also affects those who support them.

What is involved?

If you would like to take part, you need to do two things.

First, fill in the consent form in this pack to say you are happy to answer the questionnaire.

Second, fill in the questionnaire in this pack and hand it back to me or the clinic receptionist. Filling in the questionnaire should take up to 10 minutes. Your family member or friend who you have attended clinic today with will also be asked to fill in a separate questionnaire (if they wish to).

Participation

It is up to you to decide whether or not to take part. You do not have to answer any questions you do not want to. You are free to withdraw from the study at any time. Please tell me about any concerns you may have

Who will have access to the details?

All the information about your participation in this study will be kept confidential to the research team.

My contact details

I am in clinic today. If you want to get in touch with me at another time, I can be contacted at:

Department of Epidemiology and Public Health
UCL
1-19 Torrington Place
London
WC1E 6BT.

My phone number is 020 7679 8283, and my email address is jenni.burt@ucl.ac.uk

Thank you very much for taking the time to read this sheet

Centre number:
Study number:
Patient Identification Number for this study:

CONSENT FORM

Title of project: The use of health care services study
Name of researchers: Professor Rosalind Raine
Ms Jenni Burt

Please initial box

1. I confirm that I have read and understand the information sheet dated 15 December 2005 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary. I also understand that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.
3. I understand that sections of my medical notes may be looked at by the researcher from University College London. I give permission for this individual to have access to my records.
4. I agree to take part in this study

Name of Patient

Date

Signature

Researcher

Date

Signature



The use of health care services questionnaire

Thank you for agreeing to complete this questionnaire.

There are four sections to the questionnaire:

- A. Your reason for this hospital visit
- B. Your use of health care
- C. Your current health
- D. Some general questions about you

Centre ID:

Participant ID:

Date:

Instructions for completion

Please read each question carefully and answer ALL of the questions.

Where there are boxes next to the responses, please tick the appropriate box or boxes:

e.g. Yes No

Where there are several responses next to each other, please circle your answer:

e.g. Not at all A little Quite a bit Very much

Where you are asked to give your own response, please write clearly in the space provided.

All your answers will be kept in the strictest confidence and used for research purposes only.

When you have completed the questionnaire, please hand it back to the researcher – Jenni Burt – who is in clinic, or to the clinic receptionist. If you do not manage to complete it whilst in clinic, please send it back to Jenni in the envelope included. You do not need to use a stamp.

A. Your reason for this hospital visit

Firstly, we would like to ask some questions about your diagnosis. For the condition for which you are being treated or examined during this hospital visit:

1. How long ago were you diagnosed with this condition or illness?
(please tick one box)

- In the past month
- In the past three months
- In the past six months
- More than six months ago

2. What was your diagnosis? (Please write it down in the space below)

.....
.....

3. Apart from this current illness, do you have any other long-standing illnesses or disabilities?

- Yes
- No

If YES, please say what these are:

.....
.....
.....

B. Your use of health care

We are interested in finding out what kind of health care you have received for *your current illness* (the condition for which you are being treated or examined during this hospital visit).

The following questions ask about the health professionals who may have treated you or who may have cared for you, since you were diagnosed with your illness.

Please remember, this does not mean you *should* have seen every one as part of your care.

Please turn over to the next section

1. Nurses

1. Lung clinical nurse specialist

Lung nurses have specialist training and experience in lung illnesses, and are based at the hospital. They provide continuing support to patients and families during and following treatment.

I have seen a lung clinical nurse specialist about my illness: (please tick box)

- Yes
- No
- Not sure
- Not applicable

2. Chemotherapy nurse

Chemotherapy nurses are hospital nurses who explain and give chemotherapy treatment to patients.

I have seen a chemotherapy nurse about my illness: (please tick box)

- Yes
- No
- Not sure
- Not applicable

3. District nurse

District Nurses visit and care for patients in their own homes. They do a whole variety of tasks, including dressing wounds, removing stitches, taking blood and giving drug treatments at home.

I have seen a district nurse about my illness: (please tick box)

- Yes
- No
- Not sure
- Not applicable

4. Specialist palliative care nurse

(sometimes called Macmillan, Ellenor or Hospice nurses)

Palliative care nurses are specialists in supporting patients and families facing illnesses such as cancer. They offer advice on pain and symptom control, and also emotional support for the patient and family. However, they do not provide 'hands-on' nursing care like the District Nurses. They often visit people in their own homes, but they may also see patients when they come as hospital outpatients, or whilst they are on a hospital ward.

I have seen a palliative care nurse about my illness: (please tick box)

- Yes
- No
- Not sure
- Not applicable

5. Research nurse

Research nurses are hospital nurses who explain participation in research studies to patients. (This question does not refer to the researcher who gave you this questionnaire)

I have seen a research nurse about my illness: (please tick box)

- Yes
- No
- Not sure
- Not applicable

6. Other nurses

If you want to, please tell us about any other types of nurses you have seen about your illness. (please write in the space below)

.....

.....

.....

.....

Please turn over to the next section

2. Doctors

1. Chest doctor

A chest (respiratory) doctor specialises in caring for patients with illnesses related to their lungs (breathing).

I have seen a chest doctor about my illness: Yes
(please tick box) No
 Not sure
 Not applicable

2. Oncologist

Oncologists are doctors who specialise in treating patients with cancer. They advise patients on chemotherapy (drug) treatment, often in the outpatient clinic. Some oncologists specialise in radiotherapy (x-ray) treatment.

I have seen an oncologist about my illness: Yes
(please tick box) No
 Not sure
 Not applicable

3. Palliative care doctor

Palliative care doctors are specially trained in the control of pain and other symptoms such as difficulties with breathing, or feeling sick (nausea) and vomiting. These doctors may see patients in the hospital outpatient clinic, on a hospital ward, or even visit some patients at home.

I have seen a palliative care doctor about Yes
my illness: (please tick box) No
 Not sure
 Not applicable

4. Other doctors

If you want to, please tell us about any other types of doctors you have seen about your illness. (please write in the space below)

.....
.....

3. Other sources of support

1. Below we have listed other professionals who may have supported you during your current illness. Please tick all those that you have seen.

I have seen this professional about my illness

	Yes	No	Not sure	Not applicable
1. GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Counsellor / psychotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Complementary therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Information worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Radiographer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Spiritual leader	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Other (please state)			
			

2. Finally, have you used any of the following to get information or support about your illness?

I have used this for my illness

	Yes	No	Not sure	Not applicable
1. A telephone helpline (for example, Cancer Backup)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. The internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Information leaflets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Other (please state)			

Please turn over to the next section

C. Your health

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no “right” or “wrong” answers. The information that you provide will remain strictly confidential.

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:				
	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:	Not at All	A Little	Quite a Bit	Very Much
31. How much did you cough?	1	2	3	4
32. Did you cough up blood?	1	2	3	4
33. Were you short of breath when you rested?	1	2	3	4
34. Were you short of breath when you walked?	1	2	3	4
35. Were you short of breath when you climbed stairs?	1	2	3	4
36. Have you had a sore mouth or tongue?	1	2	3	4
37. Have you had trouble swallowing?	1	2	3	4
38. Have you had tingling hands or feet?	1	2	3	4
39. Have you had hair loss?	1	2	3	4
40. Have you had pain in your chest?	1	2	3	4
41. Have you had pain in your arm or shoulder?	1	2	3	4
42. Have you had pain in other parts of your body? If yes, where	1	2	3	4
<hr/>				
43. Did you take any medicine for pain?				
1 No	2	Yes		
If yes, how much did it help?	1	2	3	4

D. Finally, we would like to ask some general questions about you

1. Are you...? Male Female
2. How old are you? Please write in: Years:
3. Are you...? (please tick one box)
- Married or living with a partner
 - Divorced or separated
 - Widowed
 - Or single (never married, and not living with a partner)

4. Apart from yourself, how many other adults live in your household (aged 18 or over)?

Write in number:

5. How many children live in your household (aged under 18)?

Write in number:

6. To which of the following ethnic groups would you say you belong? (please tick one box)

- | | |
|---|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Asian or Asian British |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Mixed | <input type="checkbox"/> Other (please specify:) |
| | |

7. What is your postcode?
(please note, we will not use this to contact you – it is for information only).

Write in full postcode:

8. Do you look after, or give special help to, anyone who is ill, disabled or elderly, other than in a professional capacity? (Please tick all that apply)

- Yes, a person in this household
- Yes, a person in another household
- No

If yes, please give details if you wish:

.....

9. And does anyone look after or give special help to you because of illness, disability or old age, other than in a professional capacity? (Please tick all that apply)

- Yes, a person in this household
- Yes, a person in another household
- No

If yes, please give details if you wish:

.....
.....

10. Did you complete this form by yourself, or did someone help you with any of it? (Please tick all that apply)

- I completed it by myself
- Someone read the questions to me
- Someone wrote down the answers I gave
- Someone answered the questions for me
- Someone translated the questions into my own language
- Someone helped in some other way (please write below)

.....
.....

Thank you very much for completing the questionnaire. Please return it to the researcher (Jenni) in the clinic, or to the staff at the clinic reception desk. Alternatively, you can return it in the envelope provided – no stamp is needed.

If there is anything else you would like to tell us in writing, please feel free to write it down in the space below or on a separate sheet of paper and return it to us with this questionnaire. We would be very interested in what you have to say.

.....
.....
.....

Thank for your help.

The use of health care services study

Participant Information Sheet

I would like to invite you to take part in a research study. Please take time to read the following information carefully and discuss it with others if you wish.

My name is Jenni Burt and I am a researcher supported by a grant from the Medical Research Council. I work for University College London (UCL). Please ask me if there is anything that is not clear or if you would like more information.

Thank you for reading this.

Purpose

In this study we would like to find out more about what type of health care patients with lung illnesses receive. We want to know if there are differences between particular groups of patients in the care they receive, and why this might be happening. It is important for us to include family members and friends, as well as patients, in this study so we can know how the treatment and care patients receive also affects those who support them.

What is involved?

If you would like to take part, you need to do two things.

First, fill in the consent form in this pack to say you are happy to answer the questionnaire.

Second, fill in the questionnaire in this pack and hand it back to me or the clinic receptionist. Filling in the questionnaire should take up to 10 minutes. Your family member or friend who you have attended clinic today with will also be asked to fill in a separate questionnaire (if they wish to).

Participation

It is up to you to decide whether or not to take part. You do not have to answer any questions you do not want to. You are free to withdraw from the study at any time. Please tell me about any concerns you may have

Who will have access to the details?

All the information about your participation in this study will be kept confidential to the research team.

My contact details

I am in clinic today. If you want to get in touch with me at another time, I can be contacted at: the Department of Epidemiology and Public Health, UCL, 1-19 Torrington Place, London, WC1E 6BT. My phone number is 020 7679 8283, and my email address is jenni.burt@ucl.ac.uk

Thank you very much for taking the time to read this sheet

Centre number:
Study number:
Participant Identification Number for this study:

CONSENT FORM

Title of project: The use of health care services study
Name of researchers: Professor Rosalind Raine
Ms Jenni Burt

Please initial box

1. I confirm that I have read and understand the information sheet dated 15 December 2005 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary. I also understand that I am free to withdraw at any time, without giving any reason, and without our medical care or legal rights being affected.
- 3.. I agree to take part in this study

Name of Participant

Date

Signature

Researcher

Date

Signature

The experiences of family and friends questionnaire

Thank you for agreeing to complete this questionnaire.

There are three sections to the questionnaire:

- A. Your reason for this hospital visit
- B. Your experiences as a family member or friend
- C.. Some general questions about you

Centre ID:

Participant ID:

Date:

Instructions for completion

Please read each question carefully and answer ALL of the questions.

Where there are boxes next to the responses, please tick the appropriate box or boxes:

e.g. Yes No

Where there are several responses next to each other, please circle your answer:

e.g. Not at all A little Quite a bit Very much

Where you are asked to give your own response, please write clearly in the space provided.

All your answers will be kept in the strictest confidence and used for research purposes only.

When you have completed the questionnaire, please hand it back to the researcher – Jenni Burt – who is in clinic, or to the clinic receptionist. If you do not manage to complete it whilst in clinic, please send it back to Jenni in the envelope included. You do not need to use a stamp.

A. Your reason for this hospital visit

Firstly, we would like to ask some questions about you and the reason for your visit to hospital today.

1. What is your relationship to the patient you are accompanying to the outpatient clinic today?

- Husband/wife/partner
- Son/daughter
- Brother/sister
- Other family member (please describe)

.....

- Friend
- Other (please describe)

.....

2. Do you normally live in the same house as your family member/friend who is attending clinic today?

- Yes
- No

3. Do you look after, or give special help to, your family member/friend you have attended clinic with today, as a result of their illness?

- Yes
- No

4. What care or support do you provide to your family member/friend?
(Please tick all boxes that apply)

- Household tasks (such as cleaning)
- Shopping / collecting benefits / prescriptions
- Accompanying to medical appointments
- Personal care (help to wash and dress, use the toilet)
- Nursing/medical care
- Emotional support
- Regular night care
- Help with money
- Other (please give details)

.....

.....

B. Your experiences as a family member or friend

We want to know how your health has been in general over the last few weeks. Please read the questions below and each of the four possible answers. Circle the response that best applies to you. Thank you for answering all the questions.

Have you recently?

1. Been able to concentrate on what you're doing	Better than usual	Same as usual	Less than usual	Much less than usual
2. Lost much sleep over worry	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Felt you were playing a useful part in things	More so than usual	Same as usual	Less useful than usual	Much less than usual
4. Felt capable of making decisions about things	More so than usual	Same as usual	Less so than usual	Much less capable
5. Felt constantly under strain	Not at all	No more than usual	Rather more than usual	Much more than usual
6. Felt you couldn't overcome your difficulties	Not at all	No more than usual	Rather more than usual	Much more than usual
7. Been able to enjoy your normal day-to-day activities	More so than usual	Same as usual	Less so than usual	Much less than usual
8. Been able to face up to your problems	More so than usual	Same as usual	Less so than usual	Much less able
9. Been feeling unhappy and depressed	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Been losing confidence in yourself	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been thinking of yourself as a worthless person.	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Been feeling reasonably happy, all things considered	More so than usual	About the same as usual	Less so than usual	Much less than usual

General Health Questionnaire (GHQ-12) © David Goldberg 1978; reproduced by permission of NFER-NELSON. All rights reserved.

3. Finally, we would like to ask some general questions about you

1. Are you...? (please tick one box)

- Male
- Female

2. How old are you?

Please write in: Years:

3. Are you...? (please tick one box)

- Married or living with a partner
- Divorced or separated
- Widowed
- Or single (never married, and not living with a partner)

4. Apart from yourself, how many other adults live in your household (aged 18 or over)?

Write in number:

5. How many children live in your household (aged under 18)?

Write in number:

6. To which of the following ethnic groups would you say you belong? (please tick one box)

- White
- Asian or Asian British
- Black or Black British
- Chinese
- Mixed
- Other (please specify):

.....

7. What is your postcode? (please note, we will not use this to contact you – it is for information only).

Write in full postcode:

8. Not including the person you attended clinic with today, do you look after, or give special help to, anyone who is ill, disabled or elderly, other than in a professional capacity? (Please tick all that apply)

- Yes, a person in this household
- Yes, a person in another household
- No

9. And does anyone look after or give special help to you because of illness, disability or old age, other than in a professional capacity? (Please tick all that apply)

- Yes, a person in this household
- Yes, a person in another household
- No

If yes, please give details if you wish:

10. Did you complete this form by yourself, or did someone help you with any of it? (Please tick all that apply)

- I completed it by myself
- Someone read the questions to me
- Someone wrote down the answers I gave
- Someone answered the questions for me
- Someone translated the questions into my own language
- Someone helped in some other way (please write below)

.....

.....

Thank you very much for completing the questionnaire. Please return it to the researcher (Jenni) in the clinic, or to the staff at the clinic reception desk. Alternatively, you can return it in the envelope provided – no stamp is needed.

If there is anything else you would like to tell us in writing, please feel free to write it down on in the space below or on a separate sheet of paper and return it to us with this questionnaire. We would be very interested in what you have to say.

.....

.....

**Use of health care services study
Data extraction form**

Patient details		
1	Patient identification number:	
2	Date recruited: / /
3	Site recruited from:	
	Originating site:	
4	Sex (circle):	F M
5	Date of birth: / /
6.	Postcode:	
7.	Name of GP:	
8.	Address of GP:
9.	Referred to DN (circle)	Yes No

Treatment: surgery		
1.	Surgery (circle):	Yes No
	Date: / /
	Site:	
2.	Further surgery (circle):	Yes No
	Date: / /
	Site:	
3.	Notes:

Treatment: radiotherapy		
1.	Radiotherapy (circle):	Yes No
	Date commenced: / /
	Date completed: / /
	Type (circle):	Radical Palliative Unknown
	Site:	Course (strength/#):
2.	Further RT:	Yes No
	Date commenced: / /
	Type (circle):	Radical Palliative Unknown
	Site:	Course (strength/#):
3.	Notes:

Treatment: chemotherapy		
1.	Chemotherapy (circle):	Yes No
	Date commenced: / /
	Date completed: / /
	Type (circle):	Adjuvant Palliative Unknown
	Type (circle):	Cisplatin Etoposide
		Gemcitabine Paclitaxel
		Vinorelbine Carboplatin
		Cisplatin Docetaxel
		Other:
	Number of cycles planned received
2.	Further CT (circle):	Yes No
	Date commenced: / /
	Date completed: / /
	Type (circle):	Cisplatin Etoposide
		Gemcitabine Paclitaxel
		Vinorelbine Carboplatin
		Cisplatin Docetaxel
		Other:
	Number of cycles planned received
3.	Notes:	----- -----

Use of SPC		
1.	Referral to SPC (circle):	Yes No
2.	Date of first referral: / /
3.	Referred by:	<input type="checkbox"/> Lung CNS
		<input type="checkbox"/> Chest consultant <input type="checkbox"/> Chest SPR
		<input type="checkbox"/> Oncology consultant <input type="checkbox"/> Oncology SPR
		<input type="checkbox"/> Other:
4.	Type of service (tick):	<input type="checkbox"/> Community <input type="checkbox"/> Day hospice
		<input type="checkbox"/> Inpatient hospice <input type="checkbox"/> Inpatient hospital
5.	Reason for referral	<input type="checkbox"/> Pain/symptom control
		<input type="checkbox"/> Emotional/psychological support
		<input type="checkbox"/> Social/financial
		<input type="checkbox"/> Assessment for hospice admission
		<input type="checkbox"/> Carer support
		<input type="checkbox"/> Other reason (e.g. spiritual/lymphoedema)
6.	Urgent referral (circle):	Yes No
7.	Referrer's expectations of current treatment	<input type="checkbox"/> Symptom control <input type="checkbox"/> Life prolonging
		<input type="checkbox"/> Curative
8.	Estimated prognosis	<input type="checkbox"/> Days <input type="checkbox"/> Weeks
		<input type="checkbox"/> Months <input type="checkbox"/> Years
9.	Notes:

Appendix VI

Journal papers arising from this work

This appendix contains the text of two published papers arising so far from this work:

1. Burt J, Raine R. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. *Age and Ageing* 2006 35(5): 469-476
2. Burt J, Plant H, Omar R, Raine R. Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients. *Palliative Medicine* 2010

The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review

Abstract

Objective

To investigate variations in the use of specialist palliative care services for adult cancer patients, in relation to age.

Design

Systematic review of studies examining use of or referral to specialist palliative care services in adult cancer patients.

Search strategy and selection criteria

Five electronic databases (Medline, Embase, Web of Science, HMIC, SIGLE and AgeInfo) were searched for studies published between 1966 to March 2005, and references in the articles identified were also examined. Inclusion criteria were all studies which provided data on age in relation to use of, or referral to specialist palliative care. Two reviewers independently selected studies, extracted data and assessed methodological quality according to defined criteria.

Main outcome measures

Use of or referral to specialist palliative care services, determined from all sources of report (patient, informal carer, healthcare professional, healthcare records).

Results

14 studies were identified. All reported a statistically significant lower use of specialist palliative care among older cancer patients (65 and above or older) at a univariate level (crude odds ratios ranged from 0.33 (0.15 to 0.72) to 0.82 (0.80 to 0.82)). However, there were important methodological weaknesses in all of the studies identified; most crucially, studies failed to consider variations in use in relation to need for specialist palliative care.

Conclusions

There is some evidence that older people are less likely to be referred to, or use specialist palliative care. These findings require confirmation in studies using prospectively collected data which control for patient's need for specialist palliative care.

Introduction

As populations age and disease patterns change, the need for access to high quality palliative care at the end of life is becoming of increasing public health concern. (1) For the growing numbers of older people with advanced, progressive illnesses, poor access to effective symptom control and psychosocial support as they near the end of life can lead to an increased risk of hospital admission and death in hospital. (2) Older people frequently present with complex needs as a result of comorbidities, social isolation, frail older care-givers, and economic hardship. They may respond well to the expertise offered by specialist palliative care providers across all settings. (2) However, recent UK policy documents including the NHS Cancer Plan and the National Service Framework for Older People report that that older people have poorer access to palliative care compared with younger people. (3;4)

The debate about the appropriateness of rationing health care provision by age has been fuelled recently by a National Institute for Clinical Excellence (NICE) consultation document on social value judgments, which concluded that “where age is an indicator of benefit or risk, age discrimination is appropriate.” (5) The concept of a “fair innings” has also been used to justify the prioritisation of health care resources to younger people. (6) However, these arguments refer to health care aimed at prolonging life, and are not applicable to palliative care, an intervention which improves the quality, rather than the length of life. (7)

Two previous reviews have investigated variations in access to specialist palliative care (SPC). (8;9) On the basis of seven studies published between

1997 and 2003, Ahmed et al concluded that there was some evidence that patients aged 65 and over have a reduced likelihood of referral to SPC. (8) Grande et al reviewed 14 studies and found that that older patients were less likely to receive home SPC. (9) However, neither review quantified the difference in use by younger and older patients to enable estimation of the scale of the problem. In addition, neither review applied a quality assessment to the included studies, which limits the confidence that can be placed in the conclusions.

This review is the first to critically appraise published quantitative research on the effect of age on referral to and use of SPC for patients with cancer, and to quantify the impact of age on use. Cancer patients were chosen because they represent 95% of specialist palliative care users in the UK. (10)

Review methods

Search strategy and selection criteria

We searched Medline, Embase, Web of Science, HMIC, SIGLE and AgeInfo from 1966 to March 2005 for all studies which included quantitative data on referral to and/or use of specialist palliative care (SPC) by adult cancer patients (at any site and stage of disease), across all clinical settings. Settings included in-patient care in a designated palliative care unit (e.g. hospice), day care in a designated palliative care unit, home care received from a SPC team and hospital care received from a SPC team. Studies of care not provided by a dedicated SPC team, including generalist palliative care provided by e.g. family doctors and palliative radiotherapy, were excluded. Retrospective or prospective cohort studies, case-control studies and cross-

sectional surveys were eligible for inclusion if they provided data on and included age within their analysis, even if age was not their primary predictor variable. All sources of report of referral or use (patient, informal carer, healthcare professional, healthcare records) were eligible for inclusion. There were no restrictions on the country of research, but the language of publication was restricted to English.

A combination of text words and thesaurus terms were used for two major search concepts and their synonyms – *referral/use* and *specialist palliative care* (Appendix 1 for full strategy). The search strategy was developed in Medline and then adapted for other databases. Bibliographies of full-text articles identified through database searching and included in the review were scrutinized for further relevant studies. The lists of titles, abstracts and then full texts were scrutinized independently by two reviewers (JB and RR) to determine whether they met the inclusion criteria.

Data extraction, appraisal and synthesis

Extraction of data from each paper was performed by one reviewer (JB) and checked by a second (RR). Discrepancies were resolved by referral to the original studies. A checklist was used to extract data on the methods (including design, completeness of outcome ascertainment, analysis); size of study; study population (region, subjects and inclusion/exclusion criteria); outcomes of interest; and proportions of users/non-users by age.

Components for quality assessment were adapted from the methodology checklists developed by the Scottish Intercollegiate Guidelines Network (SIGN) and used by organisations including the National Institute for Health and Clinical Excellence (NICE). (11) These series of questions, published for

study designs including cohort and case-control studies, guide assessment of the internal validity of a study. Each study-design specific checklist covers details on the selection of subjects, the assessment of outcome, confounding, and statistical analysis. Criteria are answered on a scale from 'Not reported' to 'Well covered', and an overall assessment of the study is then made based on how many of the criteria are met. Cross-sectional studies were appraised using a modified version of the cohort study checklist.

Due to the diverse nature of the included study populations and of the outcomes, statistical synthesis of study findings was inappropriate. Where data allowed, crude odds ratios and 95% confidence intervals for the use of specialist palliative care in older versus younger cancer patients were calculated. We used an age cut-off of over and under 75 where original age categories allowed. Extracted data are presented in tabular form and a narrative synthesis conducted.

Results

Description of studies

Of 2652 citations initially identified, fourteen articles (which related to thirteen studies) met the inclusion criteria. (12-25)

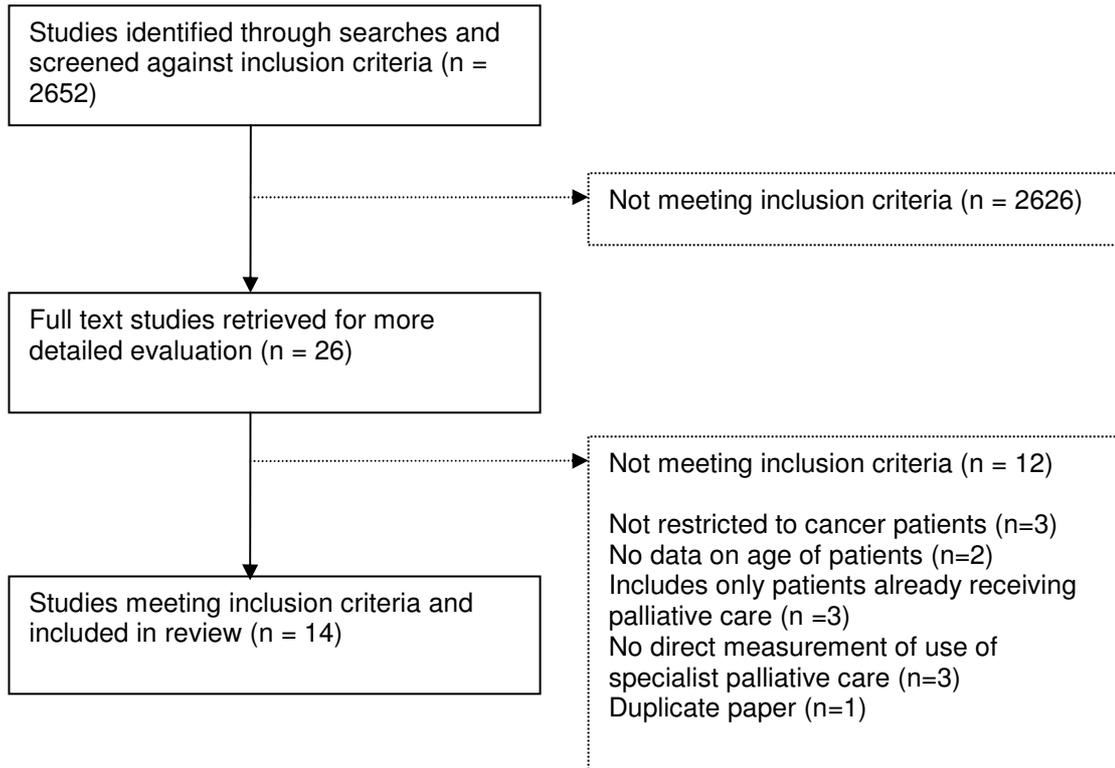


Fig 1. Flowchart of literature search and study selection

Nine of the thirteen studies were retrospective cohort studies which used administrative data and ranged in size from 521 (18) to 170,136 participants. (23) Two studies were cross-sectional surveys using retrospective reports of service use from proxy respondents (usually carers). They included 96 (24) and 2074 (12;13) participants respectively. One study used a retrospective case-control design (17) and one was a retrospective review of a palliative

care service' records, with comparisons to the wider population of cancer deaths. (16) Studies covered deaths occurring from 1979 to 1999. Two studies restricted participants to patients aged 65 years and above at death, and one to 67 years and above; the remaining restricted participants to adults, or had no stated age restrictions (Table 1).

Four articles focused specifically on the receipt of SPC at home. (13;15;17;24) The remaining included one or more services providing SPC across a range of settings (e.g. home, hospital, and hospice). Studies based their outcome ascertainment on records kept or provided by the SPC service of interest, except the two surveys of proxy respondents, which relied on participant's reports of the deceased's use of services

Use of specialist palliative care in relation to age

All of the studies reported a statistically significant lower use of SPC among older cancer patients at a univariate level. Crude odds ratios for the use of SPC in older versus younger cancer patients ranged from 0.37 (0.23 to 0.60) to 0.82 (0.80 to 0.84) (Table 2).

Eight studies included a multivariate regression analysis to investigate the effect of age on referral to or use of SPC, after controlling for potential confounding factors. (12-14;17;19-21;23) Of these, six reported older adults were significantly less likely to use specialist palliative care services. (12-14;19-21) However, age group cut-offs and variables included in regression models varied between studies, making direct comparison between them difficult. In Grande et al's (2002) case control study, the effect of age disappeared after controlling for other variables, including use of cancer and

district nursing services. (17) As the author's acknowledged, if age is related to use of other health care services, its relationship with hospice use may have been disguised in their analysis. The final study reported that, following multiple regression analysis, the effect of age (as a continuous variable) on the use of hospice care increased over the period of their study, 1991 to 1999. (23)

Discussion

Our findings suggest that patients' age may be an influential factor in use of or referral to SPC, with older patients less likely to receive these services than younger patients. However, important weaknesses in the studies reviewed limit the certainty of the findings.

Crucially, these studies did not explicitly explore the issue of *inequality* versus *inequity* of use. Inequality and inequity are related, but not equivalent, concepts. Inequities in the use of health care are inequalities (differences) in use which are considered to be unfair or unjust. (26) The judgement as to what is unfair or unjust is usually based on consideration of the need for health care and the extent to which health care inequalities are avoidable. An equitable health care system is one in which there is equal use of health care for equal need. Therefore, the measurement of need is fundamental to studies of the fair use of health care. (27) This concept of fairness, rather than simply of equality, is widely recognised when the distribution of NHS care is considered. For example, standard one of the National Service Framework (NSF) for Older People states that "NHS services will be provided, regardless of age, on the basis of clinical need alone." (4) Specialist palliative

care is designed to meet only the most complex or persistent needs of cancer patients – and therefore not all patients require this care. (28)

Unequal use of health care between particular population groups is not inequitable if it reflects an unequal need for care. These findings may therefore reflect a reduced need for specialist palliative care amongst older people. It is not yet clear whether this is indeed the case, for two reasons. First, although it has been agreed that specialist palliative care should be reserved for those with “complex and persistent” needs, there has been little examination on how this definition of need should be operationalised, resulting in a lack of agreement between medical and nursing staff as to which hospital inpatients require such care. (29) Secondly, the evidence on variations in the need for care by age, based upon the presence and impact of symptoms, is limited and conflicting. For example, one post-bereavement survey of carers found that patients over 85 years had a greater number of symptoms than patient under 65, but symptoms in the older group were less likely to “very distressing”. (30) By contrast, a secondary analysis of a retrospective survey of cancer patient carers suggested that both the number of symptoms and the proportion perceived to be “very distressing” declined with age, whilst the level of functional dependency did not vary. (31)

It is argued that the need for specialist palliative care should be determined by social, emotional and spiritual concerns as well as by health status. (1) Across a life span, patients’ health, social and economic status (including the presence of dependent children or partners, the likelihood of living alone and employment status) fluctuates. It is therefore possible that the need for specialist palliative care will vary with age. However, in the absence of

explicit definitions of the needs that can be addressed by specialist palliative care, it is not possible to explore the extent to which they differ with age. Only one of the studies included in this review attempted to define patients' need for specialist palliative care, and this was limited to a consideration of symptoms. (12;13)

An alternative explanation for lower use of specialist palliative care by older patients is that their needs are being met elsewhere. Perhaps health or social care services "fill the gap" for older cancer patients. It may be that a palliative care approach is used by generalist or care of the elderly services and that these meet the needs of older cancer patients. (28) The high proportion of older cancer patients dying in care homes may also reflect another effective approach to meeting the needs of these patients. (32) However, until a greater understanding of need is developed, it is difficult to judge how far specialist palliative care needs are met by alternative care sources.

Some further limitations of the studies included in this review should be pointed out. Firstly, four studies gave an inadequate description of SPC services that were included, their setting, and the care offered, limiting their generalisability. (14;20;22;23) Secondly, the quality of the outcomes data was often poor. All the studies were based on retrospective investigations of service use, relying on routine administrative data or recall of service use by proxy respondents. It is understandable why such data sources are used in preference to prospectively collected data from patients themselves. In this field prospective data collection is challenging, due to the terminal nature of illness, and risk of loss of data due to participants' incapacity or death.

However, the limitations of retrospective methods should be recognised. For example, referral to, or use of SPC has been shown to be inconsistently recorded in patient records; (33) the validity of responses about service use and subjective symptoms from proxies such as carers is uncertain; (34) and questions asked of proxy respondents to determine use of SPC are often insufficiently comprehensive. (24) The sensitive nature of terminal illness research should not exclude the use of prospective studies. Instead discerning methods of data collection should be designed, which may include, for example, flexibility in data collection intervals and settings. If retrospective methods continue to be used, validation methods should ascertain the accuracy of their outcomes data. These could include prospective investigation of the completeness and accuracy of medical records, or cross-validation of respondent reports with data from SPC services.

Implications

This review highlights the requirement to investigate the use of SPC in relation to the need for such care to understand whether the objectives of the NHS Cancer Plan and the NSF for Older People are being fulfilled in line with the principles of the NHS. Sensitive and flexible prospective methods should be developed to examine the extent to which the use of specialist palliative care is fair. This review also highlights wider issues about how need for SPC may be defined. Although this paper is restricted to cancer patients, the ongoing debate about SPC for non-cancer patients may present an opportunity to focus on and clarify what SPC actually is and offers, and who has a need for such care.

Table 1. Characteristics and quality appraisal of studies				
Study (location)	Age of patients	Participants	Outcome	SIGN score*
Retrospective cohort studies				
Burge 2002 (Canada) (14)	No stated restrictions	4376 cancer deaths (1992 to 1997) identified from death certificates in one municipality. No stated age restrictions.	Referral to the municipality palliative care programme. Not stated how determined.	2-
Costantini 1993 (Italy) (15)	18+	12,343 cancer deaths (1986 to 1990) identified from local department of statistics in one city.	Use of the palliative home care service. Determined from clinical records of the service.	2-
Evans 1984 (UK) (16)	No stated restrictions	125 patients (referred between May 1982 and June 1983) identified from the clinical records of the service and who received continuing care. 437 cancer deaths (1982) in one district identified from the death records of the Office of Population Censuses and Surveys.	Receipt of continuing care from the multidisciplinary terminal care support team.	2-
Gray 1997 (UK) (18)	16+	521 cancer deaths (1991) identified from death register held by the Director of Public Health. Participants included if postcode of residence within District Health Authority; cancer recorded as a causal or contributory factor in death. 16 years and over.	Receipt of care from one or more specialist palliative care agencies, last 12 months of life. Determined from in-patient and day hospice records; Marie Curie and Macmillan nurse' case load diaries	2-
Hunt 1996 (Australia) (19)	No stated restrictions	2800 cancer deaths (1990) identified from Central Cancer Registry (CCR) database. Deaths attributable to a non-cancer cause – based on State death records – excluded. No stated age restrictions.	Use of one of South Australia's inpatient hospice or outreach palliative care services. Determined from lists provided by all hospice and palliative care services of their patients who died in 1990.	2-

Table 1. Characteristics and quality appraisal of studies				
Study (location)	Age of patients	Participants	Outcome	SIGN score*
Hunt 2002 (Australia) (20)	No stated restrictions	3086 cancer deaths (1999) identified from State Cancer Registry database. No stated age restrictions.	Use of one of South Australia's inpatient hospice or outreach palliative care services. Determined from lists provided by all hospice and palliative care services of their patients who died in 1999.	2-
Johnston 1998 (Canada) (21)	20+	14,494 cancer deaths (1988 to 1994) identified from death certificate data included in the Cancer Registry in one region. 20 years and over.	Referral to a comprehensive Palliative Care Program (PCP) based in one Infirmary. Inpatient unit, hospital consultation, clinic follow-up, home consultation and bereavement support. Determined from clinical records of the service.	2-
Lackan 2003 (USA) (22)	65+	25,161 breast cancer deaths (1991 to 1996) identified from Surveillance, Epidemiology and End Result (SEER) Medicare databases - population-based registry for incident cancer cases. SEER areas represent about 14% of the US population. Diagnosed with breast cancer between 1986 and 1996. Aged 65 years and over.	Receipt of hospice care. Determined by existence of a hospice claim in the hospice standard analytic file [Medicare claims].	2-
Lackan 2004 (USA) (23)	67+	170,136 breast, colorectal, lung and prostate cancer deaths (1991 to 1999) identified from Surveillance, Epidemiology and End Result (SEER) Medicare databases - population-based registry for incident cancer cases. SEER areas represent about 14% of the US population. Diagnosed with cancer between 1991 and 1996. Aged 67 years and over.	Receipt of hospice care. Determined by existence of a hospice claim in the hospice standard analytic file [Medicare claims].	2-
Virnig 2002 (USA) (25)	65+	388,511 deaths from one of seven cancers (1996) identified from the National Center for Health Statistics' Report of Final Mortality Statistics. Aged 65 years and over.	Use of hospice care. Determined from 1996 hospice claims data submitted to the Health Care Financing Administration.	2-

Table 1. Characteristics and quality appraisal of studies				
Study (location)	Age of patients	Participants	Outcome	SIGN score*
Retrospective surveys of proxy respondents				
Addington-Hall 1998 (UK) (12)	No stated restrictions	2074 of 2094 (71% response rate) cancer deaths randomly sampled from 20 self-selected health authorities. Deaths occurring in last quarter of 1990. For each death, the best informant about the deceased's last 12 months of life sought, and interviewed using a structured questionnaire.	Receipt of hospice inpatient care. Determined by respondent's recollection of the names of hospitals and hospices to which the deceased was admitted. Names cross-checked with the 1990 Directory of Hospice Services.	2-
Addington-Hall 2000 (UK) (13)	No stated restrictions	2074 of 2094 (71% response rate) cancer deaths randomly sampled from 20 self-selected health authorities. Deaths occurring in last quarter of 1990. For each death, the best informant about the deceased's last 12 months of life sought, and interviewed using a structured questionnaire.	Receipt of CSPC nursing. Determined by respondent's reports of use of these services – no further details.	2-
McCusker 1985 (USA) (24)	No stated restrictions	133 cancer deaths randomly selected from deaths in one county, December 1979 to January 1980. Surviving relatives contacted and interviewed (96/133 – 72% response rate).	Use of the county home-hospice programme.	2-
Retrospective case-control study				
Grande 2002 (UK) (17)	No stated restrictions	121 cancer patients referred to HAH from June 1994 to June 1995 (cases) and 206 cancer deaths randomly sampled from the area Cancer Registry who were not referred to HAH (control).	Referral to the Hospital at Home palliative care service. Not stated how determined.	2+

* Based on the SIGN methodological quality checklists. Code 2 ++ (High quality case-control, cohort or cross-sectional studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal), 2+ (Well conducted case control, cohort or cross-sectional studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal), 2 - (Case control, cohort or cross-sectional studies with a high risk of confounding, bias, or chance and a significant risk that the relationship is not causal). NB: retrospective studies can only score + or -.

Table 2: Estimates of use of specialist palliative care by age group						
Study	Results: Use of SPC by age		Extracted results: Crude (unadjusted) odds ratios			Multivariate analysis
			Comparison group	Odds ratio	95% CI	
Retrospective cohort studies						
Burge 2002 (14)	< 65 = 75% 65-74 = 70% 75-84 = 53% ≥85 = 38% * * NB: No numerator or denominator data shown		-	-	-	Patients older than 65 less likely to receive SPC than patients under 65. Controlled for sex, cancer type, year of death and receipt of palliative radiotherapy. Odds ratios (OR): < 65 = 1.00 65-74 = 0.72 (0.60, 0.85) 75-84 = 0.44 (0.37, 0.53) ≥85 = 0.21 (0.17, 0.27)
Costantini 1993 (15)	<55 = 8.1% (92/1142) 55-64 = 6.1% (139/2287) 65-74 = 5.0% (179/3590) 75-84 = 2.8% (110/4005) ≥85 = 1.6% (21/1319)	Over / under 75	0.41	0.33 to 0.50		Multivariate analysis not conducted to investigate use of SPC (investigated predictors of home death for patients receiving care from SPC home care service)
Evans 1984 (16)	<44 = 75.0% (9/12) 45-54 = 66.7% (18/27) 55-64 = 30.9% (29/94) 65-74 = 28.7% (41/143) 75-84 = 19.3% (23/119) ≥ 85 = 9.5% (4/42)	Over / under 75	0.37	0.23 to 0.60		Multivariate analysis not conducted
Gray 1997 (18)	Mean age at death: Use SPC: 66.6 (SD 11.9) No use SPC: 73.0 (SD 10.6)	-	-	-		Multivariate analysis not conducted
Hunt 1996 (19)	<40 = 56.7% 40-59 = 66.3% (51/90) 60-79 = 58.1% (299/451) ≥80 = 41.2% (963/1657) (248/602)	Over / under 80	0.47	0.39 to 0.57		Patients older than 80 less likely to receive SPC compared to patients under 40. Controlled for area of residence, site, survival, place of birth, other variables uncertain/not stated. ORs: <40 = 1.00 40-59 = 1.26 (0.78, 2.03) 60-79 = 0.89 (0.57, 1.39) ≥80 = 0.41 (0.26, 0.65)

Table 2: Estimates of use of specialist palliative care by age group						
Study	Results: Use of SPC by age		Extracted results: Crude (unadjusted) odds ratios			Multivariate analysis
			Comparison group	Odds ratio	95% CI	
Hunt 2002 (20)	<60 = 73.3% 60-69 = 73.6% 70-79 = 70.9% ≥80 = 58.3%	(356/486) (457/621) (778/1097) (514/882)	Over / under 80	0.54	0.46 to 0.63	Patients older than 80 less likely to receive SPC compared to patients under 60. Controlled for area of residence, country of birth, primary cancer site, survival from diagnosis. ORs: <hr/> <60 = 1.00 60-69 = 0.96 (0.72, 1.27) 70-79 = 0.83 (0.64, 1.07) ≥80 = 0.50 (0.39, 0.65)
Johnston 1998 (21)	20-74 = 50.1 % ≥75 = 35.0%	(409/817) (182/520)	Over / under 75	0.54	0.43 to 0.67	Older patients less likely to receive SPC compared to younger patients. Controlled for sex, cancer cause of death, provision of palliative radiation, year of death, time between diagnosis and death, place of residence. ORs: <hr/> 20-54 = 4.9 (3.2, 7.6) 55-64 = 3.4 (2.2, 5.1) 65-74 = 3.1 (2.1, 4.5) 75-84 = 2.1 (1.4, 3.1) ≥85 = 1.0
Lackan 2003 (22)	67-74 = 25.4% 75-84 = 22.8% 85-89 = 18.1% ≥90 = 12.3%	(1383/5443) (2432/10666) (861/4756) (528/4293)	Over / under 75	0.71	0.66 to 0.76	Effect of age in multivariate analysis not reported
Lackan 2004 (23)	67-74 = 33.1% 75-84 = 31.2% ≥85 = 24.3%	(18377/55520) (23411/75035) (9557/39329)	Over / under 75	0.82	0.80 to 0.84	Multivariate analysis showed the effect of age (as a continuous variable) on use of hospice increased between 1991 and 1999 – adjusted odds ratios for use of hospice in 1991 were 0.99 (0.99–1.00), and in 1999 0.98 (0.97–0.98)

Table 2: Estimates of use of specialist palliative care by age group						
Study	Results: Use of SPC by age		Extracted results: Crude (unadjusted) odds ratios			Multivariate analysis
			Comparison group	Odds ratio	95% CI	
Virnig 2002 (25)	65-69 = 41.8 70-74 = 45.0 75-79 = 45.3 80-84 = 45.0 85-89 = 43.1 90-94 = 41.0 ≥95 = 38.2	Rate per 100 deaths, standardised for sex and race	-	-	-	Multivariate analysis not conducted (rates standardised for sex and race)
Proxy surveys						
Addington-Hall 1998 (12)	<55 = 17.9% 55-64 = 20.9% 65-74 = 19.5% 75-84 = 15.3% ≥85 = 7.9%	(37/207) (67/321) (111/570) (105/686) (22/277)	Over / under 75	0.62	0.49 to 0.79	Being under the age of 85 years was significantly associated with an increased likelihood of receiving inpatient hospice care. Under 85 odds ratio 2.82 (1.59 – 5.00). Variables included in model not explicitly stated.
Addington-Hall 2000 (13)	<55 = 43.0% 55-64 = 39.3% 65-74 = 31.1% 75-84 = 21.1% ≥85 = 13.4%	(89/207) (126/321) (177/570) (145/686) (37/277)	Over / under 75	0.42	0.34 to 0.51	Being under the age of 75 years was significantly associated with an increased likelihood of receiving community specialist palliative care nursing. Under 75 odds ratio 1.77 (1.4 – 2.3). Variables in model – 23, including type of respondent, marital status, whether had living children and symptoms.

Table 2: Estimates of use of specialist palliative care by age group						
Study	Results: Use of SPC by age		Extracted results: Crude (unadjusted) odds ratios			Multivariate analysis
			Comparison group	Odds ratio	95% CI	
McCusker 1985 (24)	<65 = 61.9% 65-74 = 35.9% ≥75 = 34.1%	(26/42) (14/39) (14/41)	Over / under 75	0.53	0.25 to 1.15	Multivariate analysis not conducted
Retrospective case-control study						
Grande 2002 (17)	Users mean age Non-users mean age	70.5 (SD 13.8) 74.7 (SD 12.0)	-	-	-	Effect of age significant at a univariate level (difference in mean age between Hospice at Home and control groups P=.006); disappeared in multivariate logistic regression analysis. Variables in the final model predicting membership of the Hospice at Home group included non-cancer causes of death, cancer diagnosis, contact with oncologist, late start for acute hospital care, late start for district nursing input, and receipt of Marie Curie nursing care.

Appendix – search strategy

	Medline example search strategy
	1966 to March 2005 Week 1
#1	Explode "Palliative Care" / all SUBHEADINGS
#2	"Terminal Care" / all SUBHEADINGS
#3	"Hospice Care" / all SUBHEADINGS
#4	palliat* adj (care or treat* or nurs* or medic*)
#5	terminal adj (care or nurs* or medic*)
#6	hospice adj (inpatien* or care or treat* or nurs*)
#7	end*of*life adj care
#8	Macmillan adj nurs*
#9	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8
#10	"Referral and Consultation" / all SUBHEADINGS
#11	Explode "Health Services Accessibility" / all SUBHEADINGS
#12	referral
#13	utili*ation
#14	access
#15	#10 or #11 or #12 or #13 or #14
#16	#9 and #15
#17	#16 Limit to English Language

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Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients

Abstract

The equitable provision of care is a core principle of the NHS. Previous research has suggested that older cancer patients may be less likely to use specialist palliative care, but such research has been limited by retrospective design and the failure to measure clinical need. The objective of this study was to examine the extent to which the use of specialist palliative care in lung cancer patients varies by age, after accounting for need. A cross-sectional survey of patients and their carers attending four hospital lung cancer clinics in London was conducted between June 2006 and April 2007. 252 patients and 137 carers participated in the study. 39% of participants received specialist palliative care. Metastatic disease, global quality of life and the clinic where treatment was provided were associated with use of specialist palliative care. Age, gender, deprivation, living alone, current or most recent line of treatment, number of comorbidities and carer stress were not associated with receipt of such services. This suggests that, for patients within the specialist cancer care system, access to specialist palliative care is offered on the basis of need.

Introduction

The provision of health care to all those in need, irrespective of their social characteristics, is a central tenet of the NHS. The NHS Constitution for England reinforces the principle that services should be available regardless of socioeconomic characteristics, gender, ethnicity, disability, age, sexual orientation, religion or belief. (1) This commitment to equity of access to all services is enshrined in NHS policies including the NHS Cancer Plan and the National Service Frameworks (NSFs). Thus, the NSF for Older People outlines steps to tackle age discrimination throughout the NHS (2) .

The NSF for Older People highlighted concerns that older people may have limited access to specialist palliative care (SPC) services compared to younger patients. Systematic reviews conclude that there is evidence of inequalities in referral to and use of SPC services for older patients. (3-5) This does not seem to reflect patient choice or a lower need for care. (6;7) However, previous research has not comprehensively investigated and controlled for patients' clinical and psycho-social needs for care. Therefore, we cannot draw reliable conclusions about the extent to which use of SPC is equitable (i.e. reflects the need for care) for older patients. (8) Furthermore, studies have rarely considered the needs of carers as well as patients in determining use, in spite of the stated aim of SPC to improve quality of life for patients *and their families*. (9)

The aim of this research was to examine the clinical, psychosocial and socio-demographic factors associated with receipt of SPC to investigate the extent to which older patients receive the care they need. We conducted our research amongst lung cancer patients: the high incidence, short prognosis, and frequently heavy symptom burden associated with this condition makes it particularly suitable for assessment of SPC provision.

Methods

Study design

We undertook a cross sectional survey of lung cancer patients attending chest or oncology outpatient clinics at four NHS Trusts in south London between June 2006 and April 2007. We developed eligibility criteria for participation following a pilot study and in consultation with clinic staff. Inclusion criteria were: adult patients with a clinical or histological diagnosis of primary lung cancer (non-small cell (NSCLC) and small cell (SCLC)) and the ability to fully understand consent procedures and complete study instruments in English. Patients were excluded if they had received surgery with curative intent, were not aware of their cancer diagnosis, or were participating in a clinical trial. In addition, patients attending clinic for immediate medical attention or receiving results concerning disease progression were not approached at that time. These criteria were designed to avoid distressing patients at particularly sensitive times. Informal carers attending clinic with participants were also invited to take part in the study to assess the association of carer stress with SPC use. All participants received written information about the study, and gave written informed consent.

Ethical approval was sought and received from St Thomas' Hospital NHS Research Ethics Committee. Research governance approval was sought and received separately from each of the four participating Trusts.

Study instruments

Participating patients and carers completed a semi-structured questionnaire whilst waiting for their clinic appointment. The patient questionnaire included 25 items covering their stated diagnosis and other illnesses, their

use of health care services for lung cancer, and personal details (based on items developed for the National Survey of NHS Patients by the Picker Institute and others). (10) In addition, the patient questionnaire included a validated quality of life instrument, the EORTC QLQ-C30 and its lung cancer module, the LC-13. (11;12) The EORTC QLQ-C30 includes five functional scales (physical, role, emotional, cognitive, and social), a global health/quality of life scale, and single measures of symptom severity (fatigue, nausea and vomiting, pain, dyspnoea, insomnia, appetite loss, constipation, diarrhoea, and financial difficulties). The LC-13 module has one multi-item scale for dyspnoea, and single measures to assess symptoms associated with lung cancer, including dysphagia and chest pain. All scales and single items on the QLQ-C30 and LC-13 are scored from 0 to 100. High scores on the symptom scales represent a high level of symptoms, whilst high scores on the functional scales indicating a high (good) level of functioning. The time taken to complete the questionnaire ranged from ten to 30 minutes.

The carer questionnaire comprised 13 items covering their relationship and help given to the attending patient and their personal details. It also included the General Health Questionnaire 12 item version (GHQ-12). The GHQ was developed as a self-administered screening instrument to detect general psychological distress, and is used worldwide in both healthy and ill populations. (13) It comprises twelve questions covering the respondent's experience of anxiety and depression, general level of happiness, and sleep disturbance within the last few weeks. It uses a four-point response scale which can be scored in a variety of ways. (14) We scored responses using the 0011 binary method, which rates each problem as either present or absent. The threshold value to determine cases of psychological distress was set conservatively at 3/4 (four problems present) to avoid false positives. (15) The carer questionnaire took an average of five minutes to complete.

Defining and measuring need for SPC

To evaluate equity of use of a health care service (where equity is defined as equal use for equal need for health care), need for that care must be defined and measured. Need for health care is defined as a person's capacity to benefit from use of that health care. (16) Capacity to benefit from SPC, typically reserved for those with 'complex and persistent' needs, is likely to encompass not just physical, but also social, psychological and spiritual domains. (17;18) However, there is little research evidence on how need for SPC is operationalised by referrers to and providers of these services. This is essential if we are to develop a comprehensive measure of need, rather than relying on common proxies such as diagnosis or the presence of physical symptoms. (3)

The survey reported here formed one aspect of a wider programme of research investigating need for and use of SPC. (19) This included an ethnographic study of three SPC services to explore conceptualisations of need for care. We found that providers used an aspirational model of need in assessing referrals to their service, which encompassed a patient's physical symptoms, psychological and spiritual issues, and social situation, as well as carer stress.

Measures of need for SPC must reflect this holistic approach. We appraised existing instruments to measure palliative care need (20-22) but found they were not designed for patient-completion, were unsuitable for an outpatient setting, or did not reach accepted standards of psychometric robustness.

The domains of need for SPC that we identified reflected definitions of health-related quality of life (HRQL) in palliative care, covering physical comfort, psychological wellbeing, social functioning and wellbeing, spiritual

wellbeing and meaningfulness of life, physical functioning, cognitive functioning, overall perceived quality of life and quality of dying. (23;24) HRQL has been used to approximate patients' need for healthcare where validated health care needs questionnaires are not available. (25;26) This approach also enables access to an abundance of existing, psychometrically robust HRQL instruments. We therefore chose to use HRQL as an indicator of need for SPC.

We conducted a systematic review and critical appraisal of HRQL instruments used in lung cancer and palliative care to consider the psychometric properties, conceptual relevance, and applicability of 65 possible instruments to approximate need for care. (19) On the basis of this review we chose the EORTC QLQ-C30 and the LC-13 as our proxy measures of need for SPC. The primary indicator of need for SPC in our analysis was the global health/quality of life scale score.

Additional explanatory factors

Other potential explanatory factors obtained from questionnaire data were patient gender and ethnicity, whether the patient lived alone, and socioeconomic characteristics (SEC). We derived these from post code of residence, from which we obtained an Index of Multiple Deprivation (IMD) rank. (27) The IMD is a well established small-area measure widely used as a proxy indicator of SEC, including in lung cancer patients. (28) We divided IMD ranks into tertiles of deprivation (where 1 = least deprived, 2 = mid-deprived and 3 = most deprived).

In addition we obtained data from patients' medical records and records of local service providers. Potential explanatory factors derived from medical records were patient's date of birth, extent of disease (number and location

of metastases), current and previous treatment (surgery, chemotherapy, radiotherapy), known comorbidities, and clinics attended for both diagnosis and treatment. We calculated age by subtracting date of birth from date of study participation, categorised into four groups (<55, 55–64, 65–74, and 75+ years). Extent of disease was categorised as metastatic or not; line of treatment as first-line versus second or third line. Classification of comorbidity was based on seven comorbidities or groups of comorbidities which may impact on treatment decisions and prognosis in lung cancer patients (pulmonary disease, cardiovascular disease, cerebrovascular disease, other malignancies, hypertension, diabetes mellitus, and other including severe rheumatoid arthritis, ulcerative colitis and cirrhosis) (29;30). We classified patients as having 0, 1 or ≥ 2 comorbidities. Within the cancer network, patients may be diagnosed at one clinic (usually a cancer unit), but attend a different clinic for some or all of their treatment (usually the cancer centre). To assess the impact of the location of care on use of SPC, we used medical records to identify diagnosing and treating clinics (defined as the clinic patients were attending at the time of their participation in the study).

We defined use of SPC as being on the caseload of a community palliative care provider or attending palliative care outpatient clinics at the time of participation. Patients classified as using SPC were therefore currently receiving advice and support from clinical nurse specialists, clinicians and other members of the multidisciplinary SPC team, whether by telephone, at home or in the outpatient setting. Our pilot study found disparities between palliative care use as reported by patients, hospital records and SPC providers. As patients may not always know or understand the affiliations of those caring for them, or be accurate in their recall of services received, and as hospital records do not necessarily reflect referrals made in the primary care setting, we confirmed use of SPC directly from all SPC providers.

Sample size

We estimated that within the available time frame we could recruit around 250 patients. We predicted a 40% use of SPC, giving us 100 events available for analysis. (31) This would allow estimation of 10 parameters at a time with adequate precision in any multivariable regression model. (32) We therefore decided to use univariable regression with a high significance level ($p \leq 0.5$) to first eliminate the weak explanatory variables, before entering the remaining explanatory variables in the multivariable regression model.

Statistical analysis

Potential explanatory variables chosen *a priori* for our main analysis were global quality of life, age, gender, deprivation, living alone, treating clinic, metastatic disease, current or most recent treatment, and number of comorbidities. We undertook logistic regression to investigate univariable and multivariable associations between these and use of SPC. Based on the univariable results, only explanatory variables with a *P* value of less than 0.5 were included in multivariable analysis. We used backwards elimination with the threshold value for removal set at $P > 0.05$. To assess whether the same model could be achieved using a different approach, we used forward selection procedures with the same set of variables as part of a sensitivity analysis. Goodness-of-fit was assessed using the Hosmer-Lemeshow test. (33)

Other explanatory variables of interest (diagnosing clinic, carer GHQ-12 score, and additional EORTC QLQ-C30 and LC-13 scores) were not included in our main analysis as (a) they were secondary to our main hypothesis and (b) due to sample size constraints. Instead, we conducted two additional exploratory analyses. First, we identified key functional and symptom scores *a priori* to examine the association between particular dimensions of quality

of life and use of SPC. These were physical, role, emotional and social functioning, pain, nausea and vomiting, dyspnoea (measured using the more extensive LC-13 scale), fatigue, and appetite loss. We anticipated that the multivariable analysis would be constrained by multicollinearity. We used a correlation matrix (Spearman's correlation coefficients r) to examine the degree of correlation, and calculated the proportion of moderately ($r = 0.4$ to 0.7) and strongly ($r = 0.7$ to 0.9) correlated HRQL variable pairs. Weak pairwise correlation coefficients do not necessarily exclude multicollinearity in this situation, as collinearity may exist between three or more variables. (34) We therefore limited multivariable regression analyses to examining the effect of each HRQL variable in turn on use of SPC, controlling for other significant factors. As a result, models only included one HRQL variable at a time.

Secondly, we assessed the association of carer stress with use of SPC, using data from patients for whom carer GHQ-12 scores were available. We examined univariable associations between GHQ-12 score (both as a continuous and as a dichotomous (case or not) variable) and use of SPC. We then added GHQ-12 score to the multivariable model developed for the entire data set, to assess whether an association existed after controlling for other factors found to be associated with use.

We conducted all analyses using Stata (StataCorp. 2007. Statistical Software: Release 9.2. College Station, TX: Stata Corporation).

Results

Recruitment

307 eligible patients attended participating clinics during the study recruitment period, of whom 252 (82%) consented and completed the study instruments (Figure 1). Of the 252 participants, 178 (71%) attended clinic with at least one relative or friend, of whom 137 (79%) participated in the study. Table 1 summarises the demographic and clinical characteristics of the patients. In view of the small proportion (4.8%) of non-white patients, we excluded ethnicity from further analyses. A comparison of national data on lung cancer incidence (35) suggests that patients aged 75 and above were under-represented in our survey (30.2% vs. 42.5%) (Figure 2).

Use of SPC

99 (39.3%) of participants had confirmed use of SPC at the time of participation in the study. 22 patients (23%) were referred to SPC on the day of diagnosis. All of these patients had metastatic disease.

Associations between patients' clinical and demographic characteristics and their use of SPC

Univariable analyses indicated that metastatic disease, global quality of life, current or most recent line of treatment, and treating clinic were associated with use of SPC (Table 2). Patient age, gender, deprivation, living alone and the number of comorbidities were not associated with SPC.

Physical, role, emotional and social functioning dimensions of HRQL and symptoms of pain, fatigue and appetite loss were all associated with use of SPC at the 5% level of significance.

52% of carers who completed the GHQ-12 (70/135) were psychologically distressed. Complete data were available for 131 patient-carer pairs, of whom 53 (39.9%) were under SPC. For this group, GHQ-12 scores were not associated with SPC use.

In multivariable analyses, backwards and forwards elimination produced a final model containing three variables: metastatic disease, global quality of life and treating clinic (Table 3). Age (< 75 / ≥ 75 and as a continuous variable) remained not significant when forced into the final regression model. The Hosmer-Lemeshow goodness of fit test for the final model produced a P value of 0.84, indicating the model fitted the data well. In our exploratory analysis, diagnosing clinic was also significant at a univariable (P = 0.003) and multivariable level (P = 0.005).

Multivariable analysis of specific dimensions of HRQL in relation to SPC use was constrained by multicollinearity: a correlation matrix for key HRQL variables demonstrated that over three-quarters (77.8%) of the correlations had an $r > 0.4$. In separate models with treating clinic and metastatic disease, pain and fatigue showed the strongest association with receiving SPC, along with physical and role functioning (Table 4).

Discussion

We found no association between patient age and use of SPC. Receipt of such care was, however, associated with metastatic disease, patient's global quality of life, and treating (and diagnosing) cancer clinic. Patients had a high overall symptom burden, with pain, dyspnoea and fatigue reported by the majority of participants. In half of the informal carers surveyed, psychological distress was elevated, although this was not associated with use of SPC.

Strengths and weaknesses

This is the first time an investigation of SPC use has controlled for need using a psychometrically validated instrument. Furthermore, we have demonstrated the feasibility of gathering data directly from this vulnerable group of patients, rather than relying on routine data sources or carer perceptions. Our methodology enabled us to gather a wide range of potential explanatory factors directly from patients, and to confirm use of SPC with providers of care. We are therefore confident of the validity of our findings.

Another important strength of our study was the high recruitment rate, with 82% of eligible patients taking part. This increases the likely generalisability of our results. However, 46.9% of patients (n=271) attending clinic during the recruitment period were ineligible to participate in the study, primarily because they were receiving results concerning disease progression, or required immediate medical attention (56.1% of those ineligible). This decision was taken following the study pilot to ensure patients were not disturbed at a sensitive time, and could have resulted in recruitment of patients with less extensive disease or symptoms. However, participants' EORTC scores were comparable to, or worse than, reference values for NSCLC and SCLC patients, suggesting they were representative of lung cancer patients as a whole. (36)

Our inclusion of three cancer units and one cancer centre within one network in London reflects the re-organisation of cancer services throughout England since the implementation of the NHS Cancer Plan. Whilst this increases the likelihood that our findings are generalisable to other metropolitan areas, they may not apply to less urban areas with different models of SPC provision. In addition, the outpatient setting excluded lung cancer patients

following other diagnostic and treatment routes, who may have different patterns of use of SPC – this is discussed further below.

Patients over 75 years were under-represented in our sample. This may be attributable to the contribution of 48% of participants by the cancer centre, many of whom travel large distances to attend. More elderly patients may choose not to travel such distances to receive their care. In addition, older patients may be more likely to be treated as inpatients; to be cared for under different specialties including medicine for the elderly; or to be diagnosed (if at all) much later in the disease course and to remain outside the lung cancer clinic setting. (37) The consequence is that we cannot draw conclusions about the equity of SPC provision for all patients over 75 years. Additionally, we have not investigated whether timeliness of SPC referral varies by age.

Comparison with other studies

Systematic reviews of access to SPC have concluded that older patients are less likely to receive SPC compared with their younger counterparts. (3-5) However, these reviews include studies from countries outside the UK with different funding and organisation of care. The UK based research reporting lower use of palliative care services among older patients (38-40) relied on retrospective data using reports from bereaved carers and routine data sources, thus reducing the validity of the outcomes measured. (3) Previous studies also differ from this study by their inclusion of cancer, non-cancer and non-site specific cancer patients who may have followed a number of different treatment paths. (38-40)

We found that half of participating carers had significant levels of psychological distress. This figure is comparable to that found amongst carers of people with another debilitating chronic disease (Alzheimer's

disease) (41), and four times higher than that found in the general population (42), thus suggesting that our findings are valid.

Explanations for findings

Our findings suggest that, once patients are within the specialist cancer care system, SPC is made available regardless of patient age. The association of poorer global quality of life, as well as symptoms such as pain and fatigue, with SPC use suggest that referrals are responsive to patient need for care. However, we have demonstrated association rather than causation, and our data do not enable us to assess the reasons for referral to care. For example, it may be that referrers respond to the presence of advanced, metastatic disease rather than the symptoms this causes. (43) One of the consequences of the Calman-Hine cancer care reforms was an expansion in the numbers of palliative care consultants and nurses working as members of the lung cancer multidisciplinary team. This is likely to have raised the profile and understanding of SPC, and facilitated appropriate referrals to these services. (44) However, the lack of association between carer distress and use of SPC may reflect a narrow focus within participating clinics on patient need alone. Staff may not be aware of the extent of carers' distress or may not feel referral to SPC is an appropriate response. Further work is needed in this area to assess how the needs of carers can be best met. (45)

We also found that the hospital clinic within which patients were treated or diagnosed was an important determinant of SPC use. This suggests that a reduction in regional variations in access to care (a key aim of the Calman-Hine reforms) has not been fully realised, at least in terms of access to SPC. Variation in the propensity of clinics to refer to SPC has been reported elsewhere (46) and may be dependent upon individual clinic staff's attitudes towards and knowledge of SPC; the skills and availability of lung nurse

specialists; and the integration of the clinic with local SPC services. (47) The clinics studied differed in their staff composition and skill-mix: thus, the presence of a lung nurse specialist with a palliative care background in one cancer unit may explain the lower proportion of palliative care referrals compared to a clinic without a lung nurse specialist available to support patients. Additionally, there were indications that differences in perceived availability of SPC between clinics (for example, known staffing problems within local SPC services, or poor provision within the local area) may impact on the likelihood of referrals

Finally our results diverge from other studies which demonstrate the influence of age on the likelihood of lung cancer treatment. (48). The different results may be explained by different decision making criteria for referral to care which improves quality of life (such as SPC), compared to care which extends length of life. (49;50) Denial of life-extending treatments for older people may be perceived to be acceptable (e.g. on the basis of beliefs about 'good innings' or 'normal' ageing (51)), whilst age related criteria for referral to quality of life enhancing care may be perceived to be inhumane. (52) This may explain why clinicians and nursing staff are willing to refer patients to SPC regardless of age, in spite of continuing evidence of ageism in access to lung cancer treatments.

Conclusions and recommendations for further research

Our results are to some extent encouraging, suggesting that extent of patients' disease and quality of life, rather than sociodemographic characteristics such as age, are associated with SPC referral decisions within the specialist cancer care setting. However, outstanding questions remain to be resolved. The pathway to care for patients of all ages must be examined to determine whether our results apply to patients treated in settings other than

the specialist cancer care system (such as care of the elderly). Research into the SPC referral decision-making process would further understanding of concepts of need for SPC, and how variations in referrals may arise. The wide variation in use of SPC between clinics also requires further exploration, including the extent to which differences in clinic culture, provider relationships and service availability influence access to SPC.

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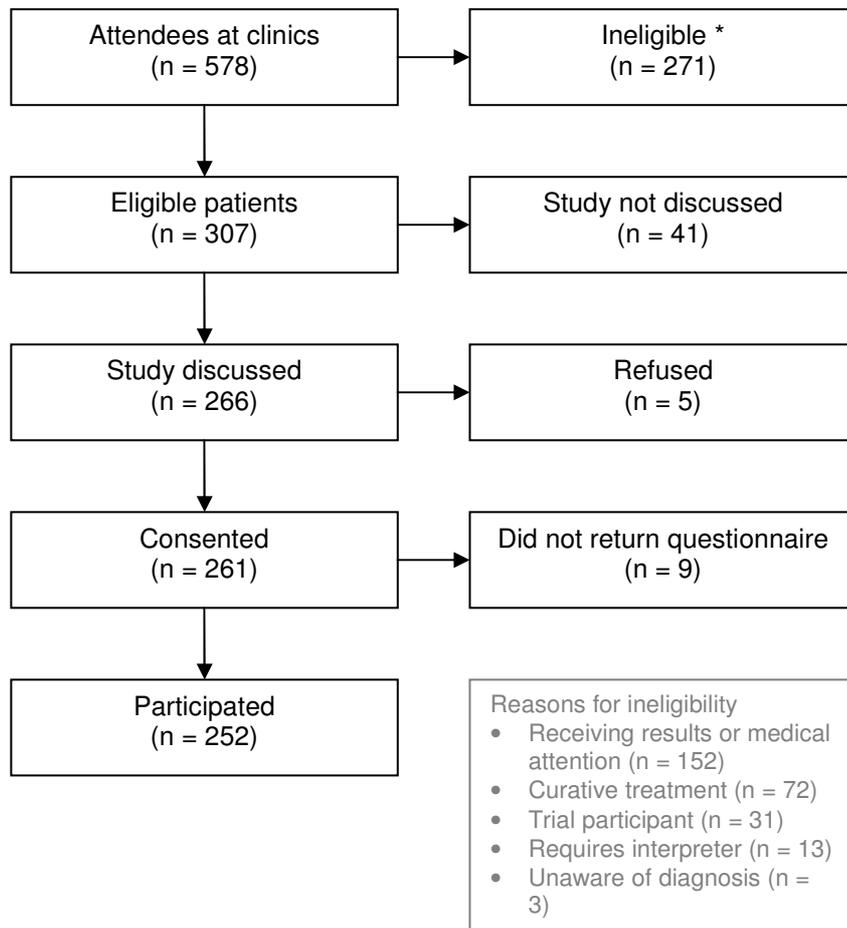
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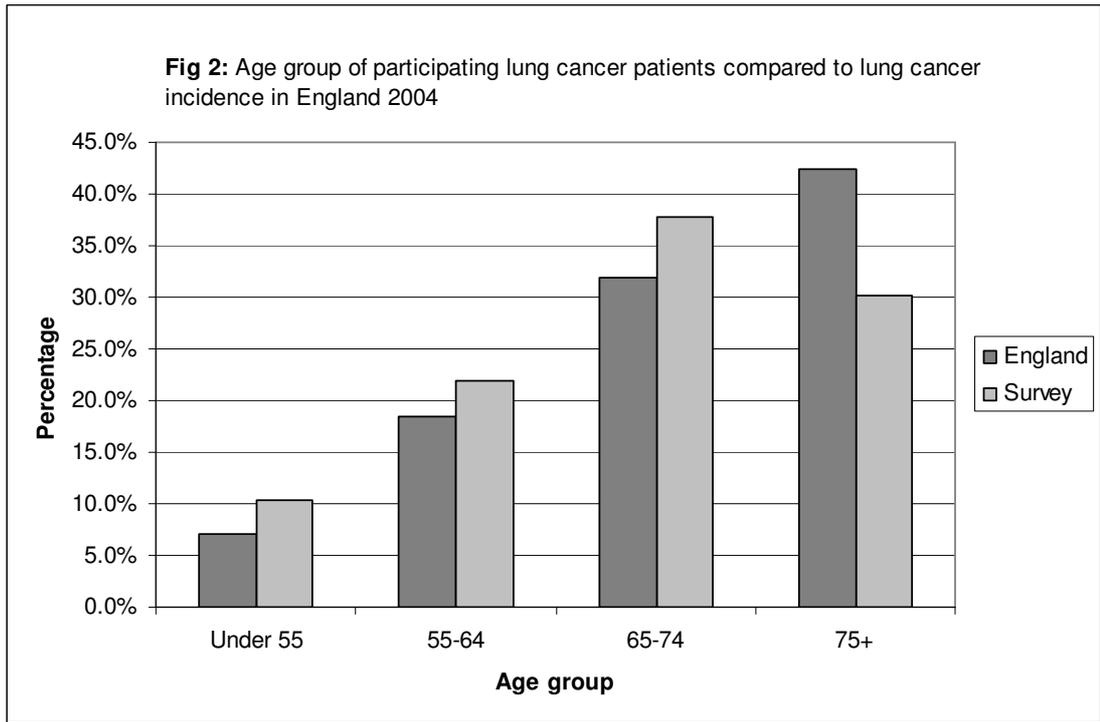
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Fig 1. Recruitment flow chart





Data for England from: Office for National Statistics. Cancer Statistics registrations: Registrations of cancer diagnosed in 2004, England. London: National Statistics; 2005

Table 1: Demographic and clinical characteristics of patients	
	n (%)
Age (years)	(n = 252)
< 55	26 (10.3)
55-64	55 (21.8)
65-74	95 (37.7)
≥ 75	76 (30.2)
Gender	(n = 252)
Male	139 (55.2)
Female	113 (44.8)
Ethnicity *	(n = 251)
White	239 (95.2)
Other	12 (4.8)
Social situation	
Lives alone	80 (31.8)
Children < 18 in household	13 (5.2)
Carer for another person	30 (12.0)
Area-level deprivation (IMD 2004)	(n = 251)
Least deprived	47 (18.7)
Mid deprived	68 (27.1)
Most deprived	136 (54.2)
Type and stage of cancer at diagnosis	
NSCLC:	184 (73.9)
Stage I	18 (10.3)
Stage II	12 (6.9)
Stage III	79 (45.4)
Stage IV	65 (37.4)
SCLC:	61 (24.5)
Limited	17 (29.3)
Extensive	41 (70.7)
Not known	4 (1.6)
Time since diagnosis	
< 1 month	13 (5.2)
1 to < 3 months	61 (24.2)
3 to < 6 months	40 (15.9)
≥ 6 months	138 (54.8)
Metastatic disease at participation	
No	109 (43.3)
Yes	143 (56.8)
Site of metastatic disease **	
Other lung	58 (33.1)

Bone	35 (20.0)
Liver	31 (17.7)
Adrenal	22 (12.6)
Brain	20 (11.4)
Other	9 (5.1)
Treating clinic	
1	121 (48.0)
2	93 (36.9)
3	24 (9.5)
4	14 (5.6)

* Excluded from analysis due to small numbers in non-white groups

** Totals add up to more than 143 as 28 patients had metastatic disease at two sites, and two patients had metastatic disease at three sites

NSCLC (Non-small cell lung cancer); SCLC (Small cell lung cancer)

Table 2: Univariable regression analysis				
	OR	95% CI		P value
Age				
Under 75	1.00			
75 and over	0.84	0.48	1.46	0.53
Gender				
Male	1.00			
Female	1.56	0.94	2.60	0.09
Deprivation				
Least deprived	1.00			
Mid deprived	1.09	0.51	2.36	
Most deprived	1.24	0.62	2.45	0.81
Living alone				
No	1.00			
Yes	1.42	0.83	2.43	0.21
Treating clinic				
1	1.00			
2	0.38	0.21	0.70	
3	2.48	0.99	6.23	
4	1.24	0.41	3.75	<0.001
Metastatic disease				
No	1.00			
Yes	2.85	1.66	4.90	<0.001
Current/most recent treatment				
First line	1.00			
Second or third line	1.95	1.02	3.75	0.045
Number of comorbidities				
None	1.00			
One	0.84	0.47	1.50	
Two or more	1.12	0.58	2.18	0.69
Global quality of life				
One unit increase	0.97	0.96	0.99	<0.001

Table 3: Final model for use of SPC				
	OR	95% CI		P value
Treating clinic				
1	1.00			
2	0.37	0.19	0.71	
3	2.43	0.90	6.52	
4	0.95	0.28	3.23	0.002
Metastatic disease				
No	1.00			
Yes	2.60	1.44	4.68	0.002
Global quality of life				
One unit increase	0.97	0.96	0.98	<0.001

Table 4: Exploratory regression analysis – use of SPC by key HRQL variables								
	Univariable analysis				Multivariable analysis: recruiting site and metastatic disease included			
	OR	95% CI	P	OR	95% CI	P	OR	P
Physical functioning								
One unit increase	0.98	0.97	0.99	<0.001	0.97	0.96	0.99	<0.001
Role functioning								
One unit increase	0.98	0.98	0.99	<0.001	0.98	0.97	0.99	<0.001
Emotional functioning								
One unit increase	0.98	0.97	0.99	0.001	0.98	0.97	0.99	<0.001
Social functioning								
One unit increase	0.99	0.98	1.00	0.002	0.99	0.98	1.00	0.005
Fatigue								
One unit increase	1.02	1.01	1.03	<0.001	1.02	1.01	1.03	<0.001
Nausea and vomiting								
One unit increase	1.01	0.99	1.02	0.202	1.01	1.00	1.02	0.184
Pain								
One unit increase	1.02	1.01	1.02	<0.001	1.02	1.01	1.03	<0.001
Dyspnoea								
One unit increase	1.01	1.00	1.02	0.038	1.02	1.00	1.03	0.006
Loss of appetite								
One unit increase	1.01	1.00	1.02	0.004	1.01	1.00	1.02	0.003

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